

**THE NATIONAL ASSOCIATION FOR THE RELIEF OF PAGET'S DISEASE**

**ANNUAL REPORT AND FINANCIAL STATEMENTS**

**FOR THE YEAR ENDED 31 DECEMBER 2019**

**Charity Registration Number 266071**

**THE NATIONAL ASSOCIATION FOR THE RELIEF OF PAGET'S DISEASE**

**FINANCIAL STATEMENTS**

**YEAR ENDED 31 DECEMBER 2019**

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**THE NATIONAL ASSOCIATION FOR THE RELIEF OF PAGET'S DISEASE**

**LEGAL AND ADMINISTRATIVE INFORMATION**

**YEAR ENDED 31 DECEMBER 2019**

<b>Registered charity name</b>	The National Association for the Relief of Paget's Disease
<b>Charity number</b>	266071
<b>Registered office</b>	Suite 5 Moorfield House Moorside Road Swinton Manchester M27 0EW
<b>Patrons</b>	Sir Henry Paget Mr Recardo Patrick The Lord Stamp MD FRCP
<b>Honorary Patrons</b>	Mrs Joyce Cupitt
<b>Trustees</b>	Dr Anna Daroszevska Dr Sheelagh Farrow Professor Roger Francis Mr. Peter Jones Professor Robert Layfield Mr. Michael Missett Mr. Michael Patnick Professor Stuart Ralston – Chairman Professor Graham Russell – Honorary President Mr. Keith Simpson Professor Michael Stone Ms. Janet Strang Dr Stephen Tuck – Vice Chairman
<b>Independent Examiner</b>	Sue Hutchinson FCCA Beever and Struthers St George's House 215-219 Chester Road Manchester M15 4JE
<b>Bankers</b>	Barclays Bank plc. 1 Market Street Bolton BL1 3NJ

## **THE NATIONAL ASSOCIATION FOR THE RELIEF OF PAGET'S DISEASE**

### **TRUSTEE'S REPORT**

#### **YEAR ENDED 31 DECEMBER 2019**

The Trustees present their report and financial statements for the year ended 31 December 2019

The financial statements have been prepared in accordance with the accounting policies set out in note 1 to the financial statements and comply with the Charity's [governing document], the Charities Act 2011 and "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)" (as amended for accounting periods commencing from 1 January 2016).

#### **The Trustees who served during the year were**

Dr Anna Daroszweska  
Dr Sheelagh Farrow  
Professor Roger Francis  
Mr. Peter Jones  
Professor Robert Layfield  
Mr. Michael Missett  
Mr. Michael Patnick  
Professor Stuart Ralston – Chairman  
Professor Graham Russell – Honorary President  
Mr. Keith Simpson  
Professor Michael Stone  
Ms. Janet Strang  
Dr Stephen Tuck – Vice Chairman

#### **Structure, governance and management**

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.

The Paget's Association is controlled by the Board of Trustees which sets strategies and policies. The main Board has three sub-committees. The role of the sub-committees 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 Professor Francis until October 2019 when he resigned as a trustee. Mr. Keith Simpson was appointed as chair from that point onwards. The Technology sub-committee was chaired throughout 2019 by Mr Peter Jones. The Research sub-committee (RSC) was chaired by Mr Michael Patnick, until October 2019 when Professor Rob Layfield took over as chair. The RSC recommended that the peer review to decide which research grants should be awarded should be delegated to a research grants committee (RGC) and suggested that this committee should be chaired by an individual without a specific interest in Paget's disease or a direct connection to the board of Trustees of the Association. This was approved by the Board of Trustees. Professor Tim Arnett, from University College London agreed to chair the RGC and co-opted Dr Frances Williams and Dr Celia Gregson as professional members and Prof George Smith as a lay member. Therefore, currently the Association has a robust and transparent system whereby external referee reports for grant applications are solicited and reviewed by the RGC. The RGC then makes a recommendation to the RSC about which grants should be funded and the RSC recommendations are then ratified by the board.

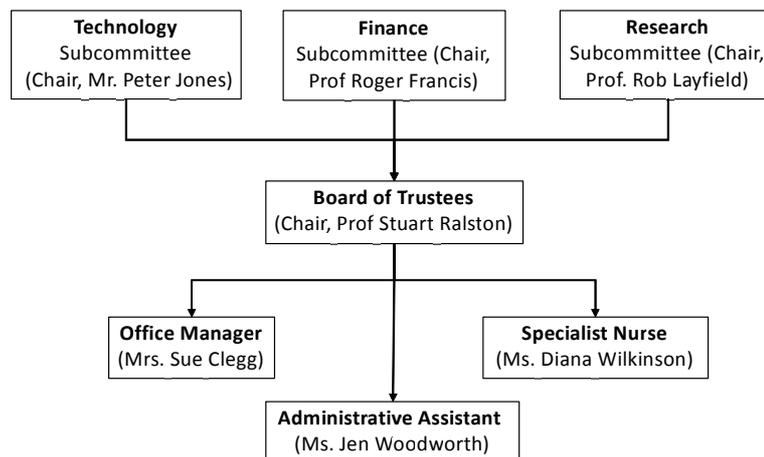
The leadership and delivery of the Association's objectives are undertaken by the staff currently based at the charity's registered office in Swinton. Due to increasing workload, the Association employed an additional full-time member of staff in June 2019 to provide administrative assistance with duties in the office, to act as a liaison officer with PACE centres and to assist the Specialist Nurse with the increasing activity in Social Media. Currently therefore, the Association currently employs three full time members of staff; an office manager, an administrative assistant, and a specialist nurse. Employees of the Association are line managed by the Chairman of the Association. The organisational structure of the charity and the chairs of each of its sub committees as of 31<sup>st</sup> December 2019 is shown in Figure 1 on page 5.

# THE NATIONAL ASSOCIATION FOR THE RELIEF OF PAGET'S DISEASE

## TRUSTEE'S REPORT

YEAR ENDED 31 DECEMBER 2019

**Figure 1. Organisational structure of the charity**



### OBJECTIVES AND ACTIVITIES

The Paget's Association is the only national charity whose remit is solely concerned with people with this condition. The specific aims of the Association are to:

- Provide information and support for people with Paget's disease and their families.
- Raise awareness about the condition both within the medical and allied health professions and amongst the general public.
- Support and fund research projects in the field of Paget's disease of bone

In the financial year ended 31 December 2019, the Association has managed to meet those aims as described below.

### ACHIEVEMENTS AND PERFORMANCE

#### Support and Raising Awareness

The Association introduced the first Paget's Awareness Day on 11th January 2019, when a Paget's Information Meeting including a webinar, took place at the James Paget Hospital, Great Yarmouth. Additional events included a Centre of Excellence Award Ceremony and patient information meeting at Manchester Royal Infirmary, patient information meetings in Edinburgh and Salford, and a professional educational meeting in Stanmore. Many hospitals displayed our information and many groups/organisations joined us to raise awareness via social media. The success of this led to it becoming an annual event.

The Association continues to provide support services for those affected by Paget's disease, their carers, health professionals and the public. These are managed by our Specialist Paget's Nurse (SPN) and include a Nurse Helpline, Paget's Support Network, local support groups and online activities. During 2019, the SPN set up a new Paget's support group in Sheffield. In addition, members are sent a quarterly magazine containing information and news regarding Paget's disease.

A summary of the 2019 clinical Guideline for the Diagnosis and Management of Paget's Disease was produced for members, professional exhibitions and our website. Three of our information booklets/leaflets were updated: The Facts about Paget's Disease of Bone; Paget's Disease of Bone - The Essential Facts; and our leaflet detailing who we are and what we do. All Paget's Association Centres of Excellence were provided with the updated information for their patients and colleagues.

The Association took an active part in the '50 Years Bisphosphonate Anniversary Conference' in Sheffield to update professionals on the latest clinical guideline and the work of the Paget's Association.

## **THE NATIONAL ASSOCIATION FOR THE RELIEF OF PAGET'S DISEASE**

### **TRUSTEE'S REPORT**

#### **YEAR ENDED 31 DECEMBER 2019**

The Association increased social media activities, using paid advertising for the first time on Facebook and Twitter, to raise awareness of both Paget's disease and the Association.

An Information Day was held in Nottingham and was filmed, to produce educational videos, which are publicly accessible online, as well as DVDs, to ensure that as many people as possible have access to the information.

An informal event took place in Runcorn at Norton Priory Museum where extensive Paget's research has been carried out on the archaeological skeletal collection. This included a short information meeting and guided tour. A Paget's research documentary was filmed separately at Norton Priory and a short trailer was circulated from November onwards, ahead of the 2020 Paget's Awareness Day.

The Association continues to provide advice to the Centre for Health and Disability Assessments, to enable them to update their staff training document regarding Paget's disease.

Towards the end of the year, the Association introduced a new website linked to a new database enabling members to manage their membership online.

Activities by members and friends of the Association helped to raise funds and raise awareness of the charity and Paget's disease. Events included the London Marathon, sponsored walks and various other events. The Trustees wish to acknowledge the efforts made by all participants of these events on behalf of the charity.

As part of its mission to raise awareness of the disease amongst health care professionals, The Paget's Association co-ordinated development of a Clinical Guideline for the Diagnosis and Management of Paget's Disease in collaboration with the European Calcified Tissues Society and the International Osteoporosis Foundation. The Guideline Development Group was chaired by Dr Stephen Tuck, vice chair of the Paget's Association and involved clinical experts from the UK, Spain, Italy and Holland, a non-clinical scientist, a specialist nurse and a patient representative. The Guideline was published in the April 2019 issue of the *Journal of Bone and Mineral Research* and has already been cited 29 times. The Guideline is mainly aimed at health care professionals in secondary care but may be of interest to GPs and other health care professionals involved in the management of Paget's disease. The Trustees agreed to cover all costs entailed in publishing the Guideline to ensure that the publication was open access.

#### **Centres of Excellence Initiative**

The Paget's Association Centres of Excellence (PACE) initiative was launched in 2015 to promote awareness, high standards of clinical care and research into Paget's Disease. Hospital and university departments which demonstrate excellence in both the treatment of Paget's disease and research into the condition were eligible to apply and currently eleven PACE centres have been established across the UK. Initially PACE Centres of Excellence were not in receipt of funding from the charity to support their work but the Trustees agreed to award a standard amount of £500 per centre, per year, to support administrative costs and £1000 per year to each centre that had enrolled patients into clinical trials or other clinical studies concerning Paget's disease. The Trustees also agreed to hold a conference to which representatives of PACE centres would be invited.

#### **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 funding of projects through advertisements on the Association's 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. 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.

The Association set aside a budget of £54,000 to cover commitments for existing research grants active during 2018 and allocated a further £60,000 for the grant round in 2019.

## **THE NATIONAL ASSOCIATION FOR THE RELIEF OF PAGET'S DISEASE**

### **TRUSTEE'S REPORT**

**YEAR ENDED 31 DECEMBER 2019**

#### **Risk Assessment**

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.

#### **Investment Policy and Performance**

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.

#### **Reserves Policy**

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 during 2019, reserves should be in place to cover at least twelve months operating expenditure, which was estimated to be in the region of £180,000 in 2020 which included £54,000 towards the cost of the Research Grants Programme in 2018. Our investments were valued at £682,204 at the 31st December 2019 and total free reserves of £1,140,551 (2018: £739,480), which is more than enough to cover twelve 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.

#### **STATEMENT OF 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 current subscription for membership of the Association to receive the quarterly newsletter is £15 per annum for UK members and £20 per annum for overseas members. 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.

The Trustees confirm that they comply with their duty to have regard to the guidance, on public benefit published by the Charity Commission in exercising their powers and duties.

#### **FINANCIAL REVIEW**

In the financial period which ended on 31 December 2019, the total income was £543,184 compared with the previous year of £447,047, mainly reflecting a substantial and somewhat unexpected increase in legacy income. The Association's total expenditure for 2019 was £188,295 compared with £172,799 the previous year. This resulted in a surplus of £354,889, before including any gains or losses in our investment portfolio, compared with a surplus of £304,248 in 2018.

Our investment portfolio was valued at £682,204 at the end of 2019 compared with £568,269 at the end of the previous year. The net gain on investments was £64,861 in 2019 compared with a loss of £40,385 the previous year which reflects volatility in markets most probably as the result of uncertainties surrounding Brexit. The overall surplus for the year was £419,750, compared with a surplus of £263,863 in 2018.

The Trustees are able to confirm that there are adequate assets to meet the Association's future expenditure plans. All ongoing and proposed expenditure can be met from existing assets although it is the Trustees' intention to seek additional funding to preserve these assets as far as possible to generate future investment income.

## **THE NATIONAL ASSOCIATION FOR THE RELIEF OF PAGET'S DISEASE**

### **TRUSTEE'S REPORT**

**YEAR ENDED 31 DECEMBER 2019**

#### **IMPLICATIONS OF COVID19 PANDEMIC**

The trustees have carefully considered the implications of the Covid19 pandemic on operation of the charity and its finances in deciding upon our plans for the future year. The pandemic did not impact appreciably on charity operations or finances during 2019 but are expected to do so during the coming year and subsequent years. Impacts and mitigating strategies are summarised below.

1. Financial planning for 2020. The pandemic has had a significant effect on the charities investments with an initial drop in investments of about 14% in overall value by 31<sup>st</sup> March 2020, from around £682,000 to £583,000) but there has been some recovery as markets have rallied, and as of 8<sup>th</sup> June 2020 our investment portfolio stands at about £642,000, a fall of only 5.7% from the end of December 2019. Given the continued uncertainty surrounding Covid-19, however, the Trustees have agreed to increase the reserves policy to ensure that we have operating funds for two years as opposed to one year previously. With the current amounts of cash at the bank and cash in hand, this can be achieved without drawing down on investments for the next two years.
2. Fundraising: The main source of charity income over the past number of years has been legacies. The charity was very fortunate to have been notified of substantial income from legacies towards the end of 2019 and so far, £210,632, from these legacies, has been received in 2020. Other fundraising activities which involve supporters organising coffee mornings, raffles and taking part in events such as marathons and sponsored walks, have been negatively impacted by Covid19 but this is not expected to affect overall financial health of the charity to any significant extent.
3. Employees: The charity adopted a work from home policy for staff members before this became official UK Government policy and has maintained this policy until the present time, except for periodic visits to the charity's headquarters to collect mail. Home working has entailed purchase of additional computer equipment and reimbursing staff for use of the internet and telephones for work related activities. Moving forward, we have plans to continue to allow employees to work from home where possible. As the Covid19 lockdown eases, the charity will ensure that should home based working not be possible for specific tasks, working patterns will be adjusted to ensure compliance with social distancing measures that are advised by UK Government.
4. Meetings: The charity cancelled plans to have a face-to-face information day originally planned for July of this year in view of UK government advice. The annual general meeting to be held in the Autumn is still planned to go ahead, with the option of attendance of delegates in person, or attendance using videoconferencing. Measures have already been put in place to allow voting on resolutions put to the AGM by post or electronic means. The board meeting originally scheduled for July 2<sup>nd</sup> 2020 as a face to face meeting has been reconfigured as a remote meeting.
5. Expenditure: The trustees have carefully reviewed the plans for the future (see section below) expenditure taking into account our income, investments and reserves policy and have agreed to the activities and initiatives set out below. We believe these initiatives will allow us to maintain the charity's objectives while keeping the charity on a sound financial footing, moving forward.

## **THE NATIONAL ASSOCIATION FOR THE RELIEF OF PAGET'S DISEASE**

### **TRUSTEE'S REPORT**

**YEAR ENDED 31 DECEMBER 2019**

#### **PLANS FOR THE FUTURE**

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 encourage further collaborative working between the twelve Paget's Association Centres of Excellence, with the aim of increasing awareness of the condition among the general public and health care professionals, improving access to services for patients with Paget's disease and facilitating research into Paget's disease. In order to achieve these aims the Trustees have agreed to continue to support PACE with an annual budget of £500 in 2020 and to offer additional annual payment of £1,000 to each centre, contingent on the centre enrolling at least 3 participants into multicentre clinical studies on Paget's disease of bone. This funding is intended to support administrative costs, participant travel, and other costs associated with clinical research that are not covered by other funds. In order to maintain this funding, centres will be required to produce an annual report documenting how they have fulfilled these objectives. A budget of £15,500 has been set aside for 2020 to support this initiative.
2. To hold a Paget's Awareness day in 2020 coinciding with the birthdate of Sir James Paget (11th January). This is anticipated to take the form of a documentary to be posted on social media focusing on research supported by the Association on a medieval form of Paget's diseases discovered to affect skeletal remains at Norton Priory.
3. To hold two patient information events during 2020.
4. To increase expenditure on social media activity with a budget of approximately £2000 during the coming year to publicise the Associations charitable objectives and activities
5. To advertise a Research Grants Round in January 2020 with an indicative budget of £151,000 and invite applications for up to two Student Research Bursaries at £6000 each. This represents a significant increase from the previous year, which has been possible due to the healthy state of the Associations finances

#### **INDEPENDENT EXAMINER**

Ms Sue Hutchinson FCCA has been re-appointed as independent examiner for the ensuing year.

The Trustees' report was approved by the Board of Trustees at their meeting on 1<sup>st</sup> July 2020

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Professor Stuart Ralston MBChB, MD, FRCP, FMedSci, FRSE, FFPM (Hon)  
Chairman, Board of Trustees

Suite 5  
Moorfield House  
Moorside Road  
Swinton  
Manchester  
M27 0EW

Dated: 10<sup>th</sup> July 2020

**THE NATIONAL ASSOCIATION FOR THE RELIEF OF PAGET'S DISEASE**

**INDEPENDENT EXAMINER'S REPORT**

**YEAR ENDED 31 DECEMBER 2019**

I report to the Trustees on my examination of the financial statements of The National Association for The Relief of Paget's Disease (the Charity) for the year ended 31 December 2019.

**Responsibilities and basis of report**

As the Trustees of the Charity you are responsible for the preparation of the financial statements in accordance with the requirements of the Charities Act 2011 (the 2011 Act).

I report in respect of my examination of the Charity's financial statements carried out under section 145 of the 2011 Act. In carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

**Independent examiner's statement**

Your attention is drawn to the fact that the charity has prepared financial statements in accordance with Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) in preference to the Accounting and Reporting by Charities: Statement of Recommended Practice issued on 1 April 2005 which is referred to in the extant regulations but has now been withdrawn.

I understand that this has been done in order for financial statements to provide a true and fair view in accordance with Generally Accepted Accounting Practice effective for reporting periods beginning on or after 1 January 2015.

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

1. accounting records were not kept in respect of the Charity as required by section 130 of the 2011 Act; or
2. the financial statements do not accord with those records; or
3. the financial statements do not comply with the applicable 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 financial statements to be reached.

Sue Hutchinson FCCA

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

Dated:

THE NATIONAL ASSOCIATION FOR THE RELIEF OF PAGET'S DISEASE

STATEMENT OF FINANCIAL ACTIVITIES  
INCLUDING INCOME AND EXPENDITURE ACCOUNTS

FOR THE YEAR ENDED 31 DECEMBER 2019

	Notes	Unrestricted funds £	Restricted Funds £	Total 2019 £	Total 2018 £
<b><u>Income and endowments from:</u></b>					
Donations and legacies	2	491,726	-	491,726	423,318
Charitable activities	3	-	-	-	2,500
Other trading activities	4	20,277	12,570	32,847	39,414
Investments	5	15,838	2,773	18,611	11,815
		<hr/>	<hr/>	<hr/>	<hr/>
Total income		527,841	15,343	543,184	477,047
		<hr/>	<hr/>	<hr/>	<hr/>
<b><u>Expenditure on:</u></b>					
Raising funds	6	10,658	-	10,658	7,440
		<hr/>	<hr/>	<hr/>	<hr/>
Charitable activities	7	162,412	15,225	177,637	165,359
		<hr/>	<hr/>	<hr/>	<hr/>
<b>Total resources expended</b>		173,070	15,225	188,295	172,799
		<hr/>	<hr/>	<hr/>	<hr/>
<b>Net income before gains/(losses) on investments</b>		354,771	118	354,889	304,248
		<hr/>	<hr/>	<hr/>	<hr/>
Net gains/(losses) on investments	10	46,300	18,561	64,861	(40,385)
		<hr/>	<hr/>	<hr/>	<hr/>
<b>Net income for the year</b>		401,071	18,679	419,750	263,863
		<hr/>	<hr/>	<hr/>	<hr/>
Fund balances at 1 January 2019		739,480	164,773	904,253	640,390
		<hr/>	<hr/>	<hr/>	<hr/>
<b>Fund balances at 31 December 2019</b>		<b>1,140,551</b>	<b>183,452</b>	<b>1,324,003</b>	<b>904,253</b>
		<hr/>	<hr/>	<hr/>	<hr/>

The statement of activities includes all gains and losses recognised in the year.

All income and expenditure derive from continuing activities.

**THE NATIONAL ASSOCIATION FOR THE RELIEF OF PAGET'S DISEASE**

**STATEMENT OF FINANCIAL POSITION**

**FOR THE YEAR ENDED 31 DECEMBER 2019**

	Note	£	2019	£	£	2018	£
<b>Fixed assets</b>							
Intangible assets	11			10,596			-
Tangible assets	12			3,182			1,227
Investments	13			<u>682,204</u>			<u>568,269</u>
				695,982			569,496
<b>Current assets</b>							
Debtors	14		399,714			3,361	
Cash at bank and in hand			240,836			336,721	
			<u>640,550</u>			<u>340,082</u>	
<b>Creditors: Amounts falling due within one year</b>	15		(12,529)			(5,325)	
Net current assets				<u>628,021</u>			<u>334,757</u>
<b>Total assets less current liabilities</b>				<u>1,324,003</u>			<u>904,253</u>
<b>Income Funds</b>							
Restricted funds	19			183,452			164,773
Unrestricted funds				1,140,551			739,480
				<u>1,324,003</u>			<u>904,253</u>

The financial statements were approved by the Trustees on 1<sup>st</sup> July 2020.

Professor Stuart Ralston - Chairman  
Trustee

THE NATIONAL ASSOCIATION FOR THE RELIEF OF PAGET'S DISEASE

STATEMENT OF CASH FLOWS

FOR THE YEAR ENDED 31 DECEMBER 2019

	2019 £	2018 £
<b>Cash flows from operating activities</b>		
Net income	419,750	263,863
<i>Adjustments for:</i>		
Depreciation	1,230	217
(Profit)/Loss on disposal of fixed assets	937	-
Dividend income	(14,523)	(12,555)
<i>Changes in:</i>		
Trade and other debtors	(396,353)	2,138
Trade and other creditors	7,204	(71,224)
Net cash from operating activities	<u>18,245</u>	<u>182,439</u>
<b>Cash flows from investing activities</b>		
Purchases of intangible fixed assets	(11,560)	-
Purchases of tangible fixed assets	(3,160)	-
Dividend income	14,523	12,555
Purchases of other investments	(126,738)	(191,272)
Sale of investments	73,611	112,313
(Increase) / Decrease in cash deposits value	(60,806)	31,498
Net cash used in investing activities	<u>(114,130)</u>	<u>(34,906)</u>
<b>Net (decrease)/increase in cash and cash equivalents</b>	<b>(95,885)</b>	147,533
<b>Cash and cash equivalents at beginning of year</b>	<u>336,721</u>	<u>189,188</u>
<b>Cash and cash equivalents at end of year</b>	<u>240,836</u>	<u>336,721</u>

# THE NATIONAL ASSOCIATION FOR THE RELIEF OF PAGET'S DISEASE

## NOTES TO THE FINANCIAL STATEMENTS

### FOR THE YEAR ENDED 31 DECEMBER 2019

#### 1. Accounting Policies

##### Charity Information

National Association for Relief of Paget's Disease in an unincorporated association governed by a Constitution and registered with the Charity Commission. The registered office is Suite 5, Moorfield House, Moorside Road, Swinton, Manchester M27 0EW.

##### 1.1 Accounting convention

The financial statements have been prepared in accordance with the Charity's [governing document] the Charities Act 2011 and "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)" (as amended for accounting periods commencing from 1 January 2019). The Charity is a Public Benefit Entity as defined by FRS 102.

The Charity has taken advantage of the provisions in the SORP for charities applying FRS 102 Update Bulletin 1 not to prepare a statement of Cash Flows.

The financial Statements have departed from the Charities (Accounts and Reports) Regulations 2008 only to the extent required to provide a true and fair view. This departure has involved following the Statement of Recommended Practice for charities applying FRS 102 rather than the version of the Statement of Recommended Practice which is referred to in the Regulations but which has since been withdrawn.

The financial statements are prepared in sterling, which is the functional currency of the Charity. Monetary amounts in these financial statement are rounded to the nearest £.

The financial statements have been prepared under the historical cost convention, modified to include the revaluation of freehold properties and to include investment properties and certain financial instruments at fair value. The principal accounting policies adopted are set out below.

##### 1.2 Going Concern

At the time of approving the financial statements, the Trustees have a reasonable expectation that the Charity has adequate resources to continue in operational existence for the foreseeable future. Thus the Trustees continue to adopt the going concern basis of accounting in preparing the financial statements.

##### 1.3 Charitable funds

Unrestricted funds are available for use at the discretion of the trustees in furtherance of their charitable objectives unless the funds have been designated for other purposes.

Restricted funds are subject to specific conditions by donors as to how they may be used. The purposes of these funds are for contributing towards Research & Education, together with funding a biennial Bone Conference in Oxford.

##### 1.4 Incoming resources

Income is recognised when the Charity is legally entitled to it after any performance conditions have been met, the amounts can be measured reliably, and it is probable that income will be received.

Cash donations are recognised on receipt. Other donations are recognised once the Charity has been notified of the donation, unless performance conditions require deferral of the amount. Income tax recoverable in relation to donations received under Gift Aid or deeds of covenant is recognised at the time of the donation.

Legacies are recognised on receipt or otherwise if the Charity has been notified of an impending distribution, the amount is known, and receipt is expected. If the amount is not known, the legacy is treated as a contingent asset.

Turnover is measured at the fair value of the consideration received or receivable and represents amounts receivable for goods and services provided in the normal course of business, net of discounts, VAT and other sales related taxes.

**THE NATIONAL ASSOCIATION FOR THE RELIEF OF PAGET'S DISEASE**

**NOTES TO THE FINANCIAL STATEMENTS**

**FOR THE YEAR ENDED 31 DECEMBER 2019**

**1. Accounting Policies (cont/d)**

**1.5 Resources expended**

Expenditure is recognised on an accrual basis as a liability is incurred.

Grants are recognised in the Statement of Financial Activities when the conditions attached to the grant award are met.

**1.6 Intangible fixed assets**

Intangible fixed assets are initially measured at cost and subsequently measured at cost or valuation, net of amortisation and any impairment losses.

Amortisation is recognised so as to write off the cost or valuation of assets less their residual values over their useful lives on the following basis.

Website / CRM Database	5 year Straight line
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**1.7 Tangible fixed assets**

Tangible fixed assets are initially measured at cost and subsequently measured at cost or valuation, net of depreciation and any impairment losses.

Depreciation is recognised so as to write off the cost or valuation of assets less their residual values over their useful lives on the following basis.

Fixed and fittings	15% Reducing balance
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The gain or loss arising on the disposal of an asset is determined as the difference between the sale proceeds and the carrying value of the asset, and is recognised in net income (expenditure) for the year.

**1.8 Fixed asset investments**

Fixed asset investments are initially measured at transaction price excluding transaction costs, and are subsequently measured at fair value at each report date. Changes in fair value are recognised in net income/(expenditure) for the year. Transaction costs are expensed as incurred.

**1.9 Impairment of fixed assets**

At each reporting end date, the Charity reviews the carrying amounts of its tangible assets to determine whether there is any indication that those assets have suffered an impairment loss. If any such indication exists, the recoverable amount of the asset is estimated in order to determine the extent of the impairment loss (if any).

Intangible assets with indefinite lives and intangible assets not yet available for use are tested for impairment annually, and whenever there is an indication that the asset may be impaired.

**1.10 Cash and cash equivalents**

Cash and cash equivalents include cash in hand, deposits held at call with banks, other short-term liquid investments with original maturities of three months or less, and bank overdrafts. Bank overdrafts are shown with borrowings in current liabilities.

**1.11 Financial instruments**

The Charity has elected to apply the provisions of Section 11 'Basic Financial Instruments' and Section 12 'Other Financial Instruments Issues' of FRS 102 to all of its financial statements.

Financial instruments are recognised in the Charity's balance sheet when the Charity becomes part to the contractual provisions of the instrument.

Financial assets and liabilities are offset, with the net amounts presented in the financial statements, when there is a legal enforceable right to set off the recognised amounts and there is an intention to settle on a net basis or to realise the asset and settle the liability simultaneously.

**Basic financial assets**

Basic financial assets, which include debtors and cash and bank balances, are initially measured at transaction price including transaction costs and are subsequently carried at amortised cost using the effective interest method unless the arrangement constitutes a financing transaction, where the transaction is measured at the present value of the future receipts discounted at a market rate of interest. Financial assets classified as receivable within one year are not amortised.

THE NATIONAL ASSOCIATION FOR THE RELIEF OF PAGET'S DISEASE

NOTES TO THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 DECEMBER 2019

1. Accounting Policies (cont/d)

**Basic financial liabilities**

Basic financial liabilities including creditors and bank loans are initially recognised at transaction price unless the arrangement constitutes a financing transaction, where the debt instrument is measured at the present value of the future payment discounted at a market rate of interest. Financial liabilities classified as payable within one year are not amortised.

Debt instruments are subsequently carried at amortised cost, using the effective interest rate method.

Trade creditors are obligated to pay for goods or services that have been acquired in the ordinary course of operations from suppliers. Amounts payable are classified as current liabilities if payment is due within one year or less. If not, they are present as non-current liabilities. Trade creditors are recognised initially at transaction price and subsequently measured at amortised cost using the effective interest method.

**Derecognition of financial liabilities**

Financial liabilities are derecognised when the Charity's contractual obligations expire or are discharged or cancelled.

1.12 **Employee benefits**

The cost of any unused holiday entitlement is recognised in the period in which the employee's services are received.

Termination and benefits are recognised immediately as an expense when the Charity is demonstrably committed to terminate the employment of an employee or to provide termination benefits.

1.13 **Retirement benefits**

Payments to define contribution retirement benefit schemes are charged as an expense as they fall due.

1.14 **Leases**

Rentals payable under operating leases, including any lease incentives received, are charged to income on a straight line basis on the term of the relevant leases.

2. Donations and legacies

	Unrestricted funds £	Restricted Funds £	Total 2019 £	Total 2018 £
Donations	80,273	-	80,273	50,567
In Memoriam	4,892	-	4,892	5,167
Legacies	398,808	-	398,808	358,528
Gift Aid	7,753	-	7,753	9,053
	491,726	-	491,726	423,318

3. Charitable activities

	Unrestricted Funds £	Restricted Funds £	2019 £	2018 £
Services to Oxford Conference	-	-	-	2,500
	-	-	-	2,500

THE NATIONAL ASSOCIATION FOR THE RELIEF OF PAGET'S DISEASE

NOTES TO THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 DECEMBER 2019

4. Other trading activities

	Unrestricted Funds £	Restricted Funds £	Total 2019 £	Total 2018 £
Membership Subscriptions	6,375	-	6,375	6,050
Pennies for Paget's Boxes	-	12,570	12,573	7,650
200 Club	6,255	-	6,255	6,105
London Marathon	5,638	-	5,638	14,383
London 100 Ride	-	-	-	775
Other Sponsorship	1,065	-	1,065	3,627
Sundry Merchandise	481	-	481	422
Sundry Fundraising	463	-	463	402
	<hr/> 20,277	<hr/> 12,570	<hr/> 32,847	<hr/> 39,414
	<hr/> <hr/>	<hr/> <hr/>	<hr/> <hr/>	<hr/> <hr/>

5. Investments

	Unrestricted Funds £	Restricted Funds £	Total 2019 £	Total 2018 £
Interest receivable	4,011	77	4,088	1,159
Dividends received	11,827	2,696	14,523	10,656
	<hr/> 15,838	<hr/> 2,773	<hr/> 18,611	<hr/> 11,815
	<hr/> <hr/>	<hr/> <hr/>	<hr/> <hr/>	<hr/> <hr/>

6. Raising Funds

	Unrestricted funds £	Restricted Funds £	Total 2019 £	Total 2018 £
London Marathon costs	2,774	-	2,774	3,901
200 Club expenses	2,100	-	2,100	2,050
Sundry merchandise	5,784	-	5,784	1,489
	<hr/> 10,658	<hr/> -	<hr/> 10,658	<hr/> 7,440
	<hr/> <hr/>	<hr/> <hr/>	<hr/> <hr/>	<hr/> <hr/>

THE NATIONAL ASSOCIATION FOR THE RELIEF OF PAGET'S DISEASE

NOTES TO THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 DECEMBER 2019

7. Charitable Activities

	Unrestricted funds £	Restricted Funds £	Total 2019 £	Total 2018 £
Grants payable	-	14,079	14,079	18,909
Staff costs	99,062	-	99,062	82,182
Premises costs	12,277	-	12,277	12,278
Conference expenses	270	-	270	3,900
Other office expenses	1,925	-	1,925	1,824
Printing, postage and stationery	17,358	-	17,358	16,728
Computer costs	2,245	-	2,245	7,350
Professional fees and Literature	990	-	990	4,506
Travel	6,982	-	6,982	7,158
Sundry costs	724	-	724	167
PR and Marketing	4,605	-	4,605	1,744
Depreciation	1,230	-	1,230	217
Loss on disposal of fixed assets	937	-	937	-
	<hr/> 148,605	<hr/> 14,079	<hr/> 162,684	<hr/> 156,963
Governance costs:				
Accountancy	2,875	-	2,875	2,563
Legal Fees	20	-	20	45
Investment managers fees	4,303	1,146	5,449	4,709
Cost of Trustee Meetings	6,103	-	6,103	546
Bank charges	506	-	506	533
	<hr/> 13,807	<hr/> 1,146	<hr/> 14,953	<hr/> 8,396
<b>Total Expenditure on Charitable Activities</b>	<hr/> <b>162,412</b>	<hr/> <b>15,225</b>	<hr/> <b>177,637</b>	<hr/> <b>165,359</b>
<b>Analysis of Grants</b>		<b>2019</b>	<b>2018</b>	
		<b>£</b>	<b>£</b>	
Research grants to Institutions		14,079	18,909	
		<hr/> <hr/>	<hr/> <hr/>	

THE NATIONAL ASSOCIATION FOR THE RELIEF OF PAGET'S DISEASE

NOTES TO THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 DECEMBER 2019

8. Trustees

None of the Trustees (or any persons connected with them) received any remuneration or benefits from the Charity during the year.

9. Employees

Number of employees

The average monthly number of employees during the year was:

	2019 Number	2018 Number
<b>Charitable activities</b>	<b>3</b>	<b>2</b>
	<hr/>	<hr/>
<b>Employment costs</b>	<b>2019</b>	<b>2018</b>
	<b>£</b>	<b>£</b>
Wages and salaries	86,609	72,536
National Insurance costs	5,695	3,854
Other pension costs	6,758	5,792
	<hr/>	<hr/>
	<b>99,062</b>	<b>82,182</b>
	<hr/>	<hr/>

10. Investments

	Unrestricted funds £	Restricted Funds £	Total 2019 £	Total 2018 £
Gain/(loss) on sale of investments	46,299	18,561	64,860	(40,385)
	<hr/>	<hr/>	<hr/>	<hr/>
<b>For the year ended 31 December 2018</b>	<b>(32,422)</b>	<b>(7,963)</b>		<b>(40,385)</b>
	<hr/>	<hr/>		<hr/>

11. Intangible fixed assets

	Website/CRM Database £
<b>Cost</b>	
At 1 January 2019	-
Additions	11,560
	<hr/>
At 31 December 2019	11,560
	<hr/>
<b>Amortisation and impairment</b>	
At 1 January 2019	-
Amortisation charged in the year	963
	<hr/>
At 31 December 2019	963
	<hr/>
<b>Carrying amount</b>	
At 31 December 2019	10,597
	<hr/>
At 31 December 2018	-
	<hr/>

THE NATIONAL ASSOCIATION FOR THE RELIEF OF PAGET'S DISEASE

NOTES TO THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 DECEMBER 2019

12. Tangible fixed assets

	<b>Fixtures and fittings £</b>
<b>Cost</b>	
At 1 January 2019	2,610
Additions	3,160
Disposals	(1,994)
At 31 December 2019	<u>3,776</u>
<b>Depreciation and impairment</b>	
At 1 January 2019	1,383
Depreciation charged in the year	267
Depreciation eliminated on disposals	(1,057)
At 31 December 2019	<u>594</u>
<b>Carrying amount</b>	
At 31 December 2019	<u>3,182</u>
At 31 December 2018	<u>1,227</u>

13. Fixed asset investments

	<b>Listed Investments £</b>	<b>Cash in Portfolio £</b>	<b>Total £</b>
<b>Cost or valuation</b>			
At 1 January 2019	559,633	8,636	568,269
Additions	126,738	-	126,738
Valuation changes	64,860	-	64,860
Movement in cash held	-	60,806	60,806
Disposals	(138,469)	-	(138,469)
At 31 December 2019	<u>612,762</u>	<u>69,442</u>	<u>682,204</u>
<b>Carrying amount</b>			
At 31 December 2019	<u>612,762</u>	<u>69,442</u>	<u>682,204</u>
At 31 December 2018	<u>559,633</u>	<u>8,636</u>	<u>568,269</u>

**Fixed asset investments revalued**

Fixed asset investments are initially measured in transaction price excluding transaction costs, and are subsequently measure at fair value at each reporting date. Changes in fair value are recognised in net income/(expenditure) for the year and split between unrestricted funds and restricted funds based on investment portfolio split. Transaction costs are expensed as incurred.

THE NATIONAL ASSOCIATION FOR THE RELIEF OF PAGET'S DISEASE

NOTES TO THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 DECEMBER 2019

14. Financial instruments

	2019 £	2018 £
<b>Carrying amount of financial assets</b>		
Equity instruments measured at cost less impairment	612,762	559,633

15. Debtors

	2019 £	2018 £
<b>Amount falling due within one year</b>		
Prepayments and accrued income	399,714	3,361

16. Creditors: amounts falling due within one year

	2019 £	2018 £
Accruals and deferred income	12,529	5,325

17. Research Grant Commitment over 12 months

The Charity has agreed to award Research Grants amounting to £60,000 (2018: £59,997), which are due for payment in over 12 months.

18. Charitable Funds

	Balance at 1 Jan 2019 £	Incoming Resources £	Outgoing Resources £	Balance at 31 Dec 2019 £
Unrestricted Income	739,480	574,141	173,070	1,140,551
Restricted Income	<u>164,773</u>	<u>33,904</u>	<u>15,225</u>	<u>183,452</u>
	904,253	608,045	188,295	1,324,003
	Balance at 1 Jan 2018 £	Incoming Resources £	Outgoing Resources £	Balance at 31 Dec 2018 £
Unrestricted Income	455,589	434,689	150,798	739,480
Restricted Income	<u>184,801</u>	<u>1,973</u>	<u>22,001</u>	<u>164,773</u>
	640,390	436,662	172,799	904,253

Restricted income relates to the Pennies for Paget's boxes – see note 21.

**THE NATIONAL ASSOCIATION FOR THE RELIEF OF PAGET'S DISEASE**

**NOTES TO THE FINANCIAL STATEMENTS**

**FOR THE YEAR ENDED 31 DECEMBER 2019**

**19. Analysis of net assets between funds**

	<b>Unrestricted</b>	<b>Restricted</b>	<b>Total</b>
	<b>£</b>	<b>£</b>	<b>£</b>
Fund balances at 31 December 2019 are represented by:			
Intangible assets	10,596	-	10,596
Tangible assets	3,182	-	3,182
Investment	537,368	144,836	682,204
Current assets	<u>589,405</u>	<u>38,616</u>	<u>628,021</u>
	<u>1,140,551</u>	<u>183,452</u>	<u>1,324,003</u>

**20. Related party transactions**

During the 2018 a grant award of £33,387 was made to Edinburgh University in association with Professor Stuart Ralston. Since the award was made Professor Ralston was appointed a Trustee and Chair of the Charity. Payments totalling £7,762 (2018: £2,426) have been made during the year. At the year end the balance outstanding was £23,199.

**21. Restricted Funds**

The restricted fund represents specific monies received by the Charity for the purpose of contributing towards Research and Education, together with funding a biennial bone Conference in Oxford.