Registered number: 06981121
Charity number: 1132271

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED

(A company limited by guarantee)

UNAUDITED

TRUSTEES' REPORT AND FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2020

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COMPANIES HOUSE

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
(A company limited by guarantee)

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REFERENCE AND ADMINISTRATIVE DETAILS OF THE COMPANY, ITS TRUSTEES AND ADVISERS FOR THE YEAR ENDED 31 MARCH 2020

Trustees

Jayesh Pindolia
Nicholas Jones
Ailsa Arthur
Jane Mary Guy (resigned 6 October 2019)
Robert Seaborne
Stuart Alderson (resigned 6 October 2019)
Sarah Chikhani (appointed 22 July 2020)
Rachel Thomas (appointed 22 July 2020)

Company registered number

06981121

Charity registered number

1132271

Registered office

Black Country House, Rounds Green Road, Oldbury, West Midlands, B69 2DG

Independent examiner

Crowe U.K. LLP, Black Country House, Rounds Green Road, Oldbury, West Midlands, B69 2DG

TRUSTEES' REPORT
FOR THE YEAR ENDED 31 MARCH 2020

The Trustees present their annual report together with the financial statements of the company for the year 1 April 2019 to 31 March 2020. The Annual report serves the purposes of both a Trustees' report and a directors' report under company law. The Trustees confirm that the Annual report and financial statements of the charitable company comply with the current statutory requirements, the requirements of the charitable company's governing document and the provisions of the Statement of Recommended Practice (SORP) applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102) (effective 1 January 2015) as amended by Update Bulletin 2 (effective January 2019).

Since the company qualifies as small under section 382 of the Companies Act 2006, the Strategic report required of medium and large companies under the Companies Act 2006 (Strategic Report and Directors' Report) Regulations 2013 has been omitted.

Objectives and activities

a. Policies and objectives

The objects of the Association for Glycogen Storage Disease (UK) as recorded in its Memorandum of Association, is "The relief of sickness, particularly of persons suffering from any form of Glycogen Storage Disease". The Association works to protect and promote the best interests of persons affected by GSD.

Public Benefit

The Trustees confirm that they have complied with the duty in section 17 of the Charities Act 2011 to have due regard to public benefit guidance published by the Commission in determining the activities undertaken by the Charity.

The Charity Commission in its "Charities and Public Benefit" Guidance states that there are two key principles to be met in order to show that an organisation's aims are for the public benefit: firstly, there must be an identifiable benefit and secondly, that benefit must be to the public or a section of the public. The Trustees are satisfied that the aims and objectives of the charity, and the activities reported on below to achieve those aims, meet these principles.

b. Strategies for achieving objectives

The Association acts as a vehicle of communication on GSD related matters by publishing and distributing relevant material. It contributes to the advancement of treatments and cures through sponsorship of research, studies and trials. It acts as a focus for educational, scientific and charitable activities related to GSD. The Association liaises with other GSD Associations around the world.

c. Activities undertaken to achieve objectives

The main activities are the support of patients and families; the organising of conferences and workshops to promote understanding of the disease; the publication of a newsletter; the provision of information about Glycogen Storage Disease through publications and a web site; and the provision of grants to research bodies and individuals. These activities support the objects by assisting patients; by encouraging and supporting research into the disease and by educating the medical profession and concerned members of the general public about the disease.

Objectives and activities (continued)

d. Grant-making policies

The Association receives applications for grants to support research projects in relation to Glycogen Storage Disease. Applications for grants are considered by the Board of Trustees and by members of the Association's Medical Advisory Board. Whenever possible the Association co-sponsor together with other charities or foundations. The Association also occasionally makes small grants to individual applicants for personal expenses associated with their treatment, care and well-being.

Achievements and performance

a. Review of activities

This report will list the difficulties the charity has been through in the last year yet will show that despite these problematic times the AGSD-UK continues to thrive and has a sound base on which to develop.

In August 2019, a chief executive, Neil Bradbury, was appointed to manage the charity's growth. Shortly after our Charity Director, Allan Muir, stood down to pursue his own business interests. In December 2019, Neil left the post of CEO. In March 2020, as Coronavirus turned our lives upside down, it was decided to put on hold any decision about appointing new staff. A team effort of our Specialist Care Advisor Jane Lewthwaite, our Finance Officer Jackie Henson, Trustees and volunteers, especially Andrew Wakelin has ensured that the charity has remained fit and able to tackle the changes that has been brought to the World as well as the changes within charity itself.

Our new website, which was launched in January of 2019 has been well received and praised, both nationally and internationally. We have around 3,000 visitors per month and over 7,500 page views. 35% of users are from the UK, 29% from the US and the rest from around the world. Management was transitioned from Andrew Wakelin to Jackie Henson. Our thanks to Andrew Wakelin, who has, and continues to put in many hours of much appreciated work. Our Coronavirus pages were commented on and commended by pharmaceutical companies.

The AGSD-UK's social media is being managed and grown by one of our volunteers, Lisa Massimo. She has done some excellent work.

We have successfully employed a benefits advisor, Julie Jackson, following a submission of a grant request from Sanofi-Genzyme. Overseen by Jane Lewthwaite, all of the benefit applications she has helped with have had a positive outcome.

Our 2019 conference was held at Daresbury Park Hotel, Warrington and was well attended. We welcomed 101 delegates. Bulwell Toy Library Crèche was engaged for the third year running and, as usual proved very popular. Special thanks also to the Pompe Support Team who created 120 delegate packs. Feedback analysed the advantages of attending, with social support and friendship at the top, followed by the chance to participate in new learning of the latest research and scientific updates. Guidance on disease management, relaxation and the crèche were all mentioned. Comments on potential improvements and 'What would you like at future conferences?' were noted on and will be acted on with 'more of the same' and 'more flamingos' from our junior members being the top requests.

A fundraising issue of Glisten was published with contributions from a broad variety of professionals and volunteers.

Achievements and performance (continued)

The Impact of Covid 19
Coronavirus has had an immense impact on everyone's lives and all charities have been affected. The AGSD-UK has had to cancel the annual conference, training days, family days, support group meetings. International Pompe Day was also affected and cancelled.

However, there has been an increased workload for all. Urgent care needs arose during the early months of the pandemic. These included helping people obtain home shopping slots, Covid -19 welfare checks and pro-active phone calls and emails. There were multiple enquiries regarding shielding, virtual hospital appointments, pausing treatments and webinars provided by professionals. Overall there were 155 contacts asking for advice. A Covid-19 website page was set up to help members find the latest reliable information on the pandemic. The pages were commented on and commended by one of our pharmaceutical donors.

It was decided that the annual conference would have to be cancelled. Our funders have been aware of this and have been sympathetic. In lieu of the conference a season producer has been employed to ensure the usual benefits of information exchange and support gained from meeting other members and professionals are not missed out on. Feeling part of a community, a benefit of the conference, often voiced by members, is a challenge, when under taken virtually but never the less, essential. The Winter Season 2020-2021 will last until February 2021.

A trustee, Rob Seaborne was asked to represent the AGSD-UK at the EPOC [European Pompe Consortium} at Frankfurt in February 2020. After arriving and spending an hour or so in the lobby of the conference venue, all delegates were asked to leave as there was a case of Coronavirus at the hospital next door. He arrived home fit and unscathed.

The role of the AGSD during 2020 has been necessarily reactive to the urgent care needs presented to our members. However, partly due to the development of online meetings along with the vibrant activity of industry seeking GSD treatments, there have been a number of opportunities to enable the patient voice with both industry and the health service. These have included partnerships with industry in surveys, development of websites and places on advisory boards, to mention a few. It is hoped, that some of these new ways of working will be kept and incorporated into the future work, plans and projects.

Fundraising in the time of a pandemic has not been easy for our members. Normal methods of raising money has not been possible. Despite this there has been some fantastic efforts. We are also aware of the strain and changes the pandemic has brought to our major industrial donors. We have maintained good and close relationships with all of them, all sides aware of the necessity to be adaptive to the changes in the world. Concurrently, the AGSD-UK is constantly reaching out and successfully contacting new donors.

Grants for Individuals
We were successful in gaining grants for individual people in need

• Campbell Burns Met Trust.	7 grants totalling £900.00
• React.	2 grants totalling £800.00
• Cash for Kids.	3 grants totalling £350.00 + toys
• Independence at Home.	2 grants totalling £920.00
• Bruce Wake Trust.	Re-allocated underspend of £1260.00
• Headley Charitable Trust.	1 grant of £1,000.00
• Steve Morgan Foundation.	1 grant of £750.00
• Boporan.	2 donations of £400.00 of Tesco Vouchers
• Glasspool.	1 grant of £300.00
• League of Friends Helping Hands.	1 grant of £300.00
• EIL	1 grant of £1,250.00
• AGSD-UK Hardship.	1 grant £200.00
• AGSD-UK Covid-19.	6 grants totalling £400.00

Achievements and performance (continued)

Fundraising
We would like to thank all of our volunteers who have raised money for us in this most difficult year. Georgie Thompson, Simon Attewell, Caren Taylor, Dr Florence Osborne, Jennifer Wood and Kieron Coll.

We would also like to thank our other donors who are generally biotechnology or specialist nutrition companies
- Amicus Therapeutics
- Audentes Therapeutics
- Sanofi-Genzyme Ltd
- Vitaflo International
- Roche
- Ultragenyx

We would also like to thank Warburton's who have shown their support to us.

Collaboration and NICE Scoping
Collaboration is a key word in the working of the AGSD-UK. This year has seen alliances strengthened with the Archangel Trust, MDUK, MSUK, Genetic Alliance and the LSD Collaborative. This was particularly pertinent when Sanofi took Myozyme through MHRA and a patient speaker was requested to attend. We are waiting for the outcome as to whether NEO GAA will go through for full assessment.

Specialist Care Advisor
Jane Lewthwaite has been our specialist care advisor for four years. As Pompe SCA, she is tasked with these roles.
- To make a positive difference to the lives of people affected by Pompe through providing non-clinical advice and support and information to patients, parents and caregivers.
- To enable people affected by Pompe to access a range of services with the object of improving their quality of life.
- To provide advice and support for individuals and families on a broad range of issues.
- To enable the patient voice.
- To ensure people who need the service are not excluded.

Jane's presence has been steadfast, adaptive and hard-working through this difficult year. Her care needs work has covered such areas as benefits, navigating services, grants, emotional wellbeing, travel and transport, education, equipment, housing, employment, diagnosis, social connections and introductory calls.

GSD5 – McArdle's activities
Covid-19 caused a lot of disruption, with the McArdle clinic having to move to telephone appointments for a large part of the year. It was the 10th anniversary of the walking courses, but sadly the restrictions made it impossible to run this year's course in August. Despite the pandemic, 17 new patients came to our attention during the year many newly diagnosed but one diagnosed 40 years ago. In June a paper reported the first dominant mutation in the PYGM gene, the impact of which is so different to the recessive mutations of McArdle's that it will be classed as a new GSD.

Patients from the UK were involved in two research trials, both of which are ongoing, one on ketogenic diet and one on a repurposed drug. Many patients have been included in the Euromac Registry and during the year the first paper on data from the registry was published with some fascinating insights.

The international body IamGSD has been coordinating the drafting of clinical practice guidelines for GSD5 and GSD7, with a panel of clinicians and researchers from across the world. This paper should be published in 2021 and will be a major asset.

Achievements and performance (continued)

Hepatic GSD's
A Cori comic was created by Nikki Christie and posted to children. Projects to improve support for those with hepatic GSD's are in place.

The charity is extremely grateful for the continuing support of our donors, fundraisers, grant makers, sponsors and particularly volunteers whose efforts enable the charity to maintain its' support to all people affected by GSD in the UK.

Financial review

a. Going concern

During the Covid-19 pandemic the company has not sought to employ a new CEO. It is hoped that this measure will enable the company to conserve its resources. As the pandemic eases the intent is to restructure staffing, with more administrative support to be provided to the current staff. Relationships with existing funders have remained good, coupled with the new positive relationships that have been forged with new funders during the pandemic the trustees believe that there will be no adverse effects on income arising from the Covid-19 pandemic. The company has cash resources and has no requirement for external funding. At the date of signing the accounts the unrestricted reserve stands at £16,548. The trustees have reasonable expectation that the company has adequate resources to continue in operational existence for the foreseeable future. They continue to believe the going concern basis of accounting is appropriate in preparing the annual financial statements.

b. Reserves policy

The Association holds some funds that are restricted in expenditure in support of particular GSD Types and other projects (see note 18). The general reserves are used to support the on going activities of the Association. The unrestricted general reserve now stands at £16,548 which is an decrease from the previous year (£39,726). The trustees' future focus will be on increasing income while tightly managing costs.

In line with most small charities AGSD UK aims to spend most of the funds raised during any given financial year for the benefit of its members and the public and not to build up a large general reserve. The trustees have agreed to adopt a reserve policy that seeks to carry forward an unrestricted general reserve figure that is no greater than 25% of total in year expenditure. The Trustees are currently reviewing the amount that this should be, but because future expenditure will be reduced they believe the amount to be approximately £20,000.

c. Investment policy and performance

The Association holds it cash reserves in bank deposit accounts thus eliminating investment risk and minimising any other risk to the reserves. No long term deposits are made as it is anticipated that the reserves will continue to be called upon to support a high level of activity.

Structure, governance and management

Structure, governance and management (continued)

a. Constitution

The company is registered as a charitable company limited by guarantee and was set up under a Memorandum of Association. The company is constituted under a Memorandum of Association dated 05/08/2009 and is a registered charity number 1132271. The principal object of the company is to provide "The relief of sickness, particularly of persons suffering from any form of Glycogen Storage Disease".

b. Methods of appointment or election of Trustees

The management of the company is the responsibility of the Trustees who are elected and/or co opted under the terms of the Articles of Association. Any full member of the Association may be nominated to stand for election to the Board of Trustees. The Trustees have the power to co-opt new Trustees who are then required to stand for election at the next AGM.

c. Organisational structure and decision-making policies

The Association is a membership based association, with full membership being open to anyone affected by Glycogen Storage Disease and the close family of such persons. The members elect the Board of Trustees. The Board of Trustees elects its own officers. The Board of Trustees are responsible for ensuring that the charity complies with all relevant regulations and files its annual report and accounts with the Charity Commission and Companies House.

The Board of Trustees delivers the strategy through the Charity Director and any other staff plus a range of volunteers.

The Board appoint a volunteer Co ordinator for each of the GSD Types, wherever possible. The defined role is wide ranging and is not necessarily entirely relevant or practical for each GSD Type, where the numbers affected and their needs vary enormously. The Co ordinators meet as a group three times a year for peer support and development in their role.

d. Pay policy for key management personnel

The company currently has one permanent member of staff – the Specialist Care Advisor, and three part-time members of staff. The remuneration for key management posts was benchmarked at or below market rate prior to appointment and is reviewed by Trustees annually.

e. Risk Management

The Trustees have assessed the major risks to which the company is exposed. The current major risks to the charity are primarily in the areas of operation and finance as follows:

Income generation
Cost control
Banking control
I.T. stability and security
Adoption of and adherence to policies and procedures
Loss of key personnel

The Trustees are satisfied that systems, procedures and plans are in place to mitigate exposure to major risks.

TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2020

Plans for future periods

The overall activity of the Association is guided by charitable objectives and the detail is provided in a Strategic Plan.

Statement of Trustees' responsibilities

The Trustees (who are also the directors of the company for the purposes of company law) are responsible for preparing the Trustees' report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company law requires the Trustees to prepare financial statements for each financial year. Under company law the Trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the company and of its incoming resources and application of resources, including its income and expenditure, 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 of the Charities SORP (FRS 102);
- make judgments and accounting estimates that are reasonable and prudent;
- state whether applicable UK Accounting Standards (FRS 102) have been followed, subject to any material departures disclosed and explained in the financial statements;
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the company will continue in business.

The Trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the company's transactions and disclose with reasonable accuracy at any time the financial position of the company and enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Approved by order of the members of the board of Trustees on 15 April 2021 and signed on their behalf by:

Nicholas Jones
Trustee

INDEPENDENT EXAMINER'S REPORT
FOR THE YEAR ENDED 31 MARCH 2020

Independent Examiner's Report to the Trustees of Association for Glycogen Storage Disease (UK) Limited ('the company')

I report to the charity Trustees on my examination of the accounts of the company for the year ended 31 March 2020.

Responsibilities and Basis of Report

As the Trustees of the company (and its directors for the purposes of company law) you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of the company's accounts carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

Independent Examiner's Statement

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

1. accounting records were not kept in respect of the company as required by section 386 of the 2006 Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the accounting requirements of section 396 of the 2006 Act 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; or
4. the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities [applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)].

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.

This report is made solely to the company's Trustees, as a body, in accordance with Part 4 of the Charities (Accounts and Reports) Regulations 2008. My work has been undertaken so that I might state to the company's Trustees those matters I am required to state to them in an Independent examiner's report and for no other purpose. To the fullest extent permitted by law, I do not accept or assume responsibility to anyone other than the company and the company's Trustees as a body, for my work or for this report.

Signed: Kerry Brown Dated: 19 April 2021

Kerry Brown FCA

Crowe U.K. LLP
Chartered Accountants
Black Country House
Rounds Green Road
Oldbury
West Midlands
B69 2DG

STATEMENT OF FINANCIAL ACTIVITIES (INCORPORATING INCOME AND EXPENDITURE ACCOUNT) FOR THE YEAR ENDED 31 MARCH 2020

	Note	Restricted funds 2020 £	Unrestricted funds 2020 £	Total funds 2020 £	*Total funds 2019 £*
Income from:					
Donations and legacies	4	**132,783**	**52,213**	**184,996**	*134,624*
Other trading activities	5	**4,968**	**15,676**	**20,644**	*29,428*
Investments	6	**-**	**154**	**154**	*114*
Other income	7	**8**	**-**	**8**	*3,474*
Total income		**137,759**	**68,043**	**205,802**	*167,640*
Expenditure on:					
Raising funds	8	**-**	**4,152**	**4,152**	*5,260*
Charitable activities		**124,135**	**88,847**	**212,982**	*222,775*
Total expenditure		**124,135**	**92,999**	**217,134**	*228,035*
Net income/(expenditure)		**13,624**	**(24,956)**	**(11,332)**	*(60,395)*
Transfers between funds	18	**(1,778)**	**1,778**	**-**	*-*
Net movement in funds		**11,846**	**(23,178)**	**(11,332)**	*(60,395)*
Reconciliation of funds:					
Total funds brought forward		**99,890**	**39,726**	**139,616**	*200,011*
Total funds carried forward		**111,736**	**16,548**	**128,284**	*139,616*

The Statement of Financial Activities includes all gains and losses recognised in the year.

The notes on pages 12 to 30 form part of these financial statements.

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
(A company limited by guarantee)
REGISTERED NUMBER: 06981121

BALANCE SHEET
AS AT 31 MARCH 2020

	Note		2020 £		2019 £
Fixed assets					
Intangible assets	14		**14,364**		*19,151*
Tangible assets	15		**2,180**		*1,870*
			16,544		*21,021*
Current assets					
Debtors	16	**19,691**		*29,116*	
Cash at bank and in hand		**98,194**		*96,933*	
		117,885		*126,049*	
Creditors: amounts falling due within one year	17	**(6,145)**		*(7,454)*	
Net current assets			**111,740**		*118,595*
Total net assets			**128,284**		*139,616*
Charity funds					
Restricted funds	18		**111,736**		*99,890*
Unrestricted funds	18		**16,548**		*39,726*
Total funds			**128,284**		*139,616*

The company was entitled to exemption from audit under section 477 of the Companies Act 2006.

The members have not required the company to obtain an audit for the year in question in accordance with section 476 of Companies Act 2006.

The Trustees acknowledge their responsibilities for complying with the requirements of the Act with respect to accounting records and preparation of financial statements.

The financial statements have been prepared in accordance with the provisions applicable to entities subject to the small companies regime.

The financial statements were approved and authorised for issue by the Trustees on 15 April 2021 and signed on their behalf by:

Nicholas Jones N S Jones

The notes on pages 12 to 30 form part of these financial statements.

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2020

1. General information

1.1 Company Status

The Association for Glycogen Storage Disease (UK) Limited is a company limited by guarantee in England, whose registered office is Black Country House, Rounds Green Road, Oldbury, West Midlands, B29 2DG. The company's registered number is 06981121. In the event of the company being wound up, the liability in respect of the guarantee is limited to £10 per member of the company.

2. Accounting policies

2.1 Basis of preparation of financial statements

The financial statements have been prepared in accordance with the Charities SORP (FRS 102) - 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 2015), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) and the Companies Act 2006.

Association for Glycogen Storage Disease (UK) Limited 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.

2.2 Going concern

The trustees have a reasonable expectation that the company has adequate resources to continue in operational existence for the foreseeable future. They continue to believe the going concern basis of accounting appropriate in preparing the annual financial statements.

2.3 Income

All income is recognised once the company has entitlement to the income, it is probable that the income will be received and the amount of income receivable can be measured reliably.

Income tax recoverable in relation to donations received under Gift Aid or deeds of covenant is recognised at the time of the donation.

Income tax recoverable in relation to investment income is recognised at the time the investment income is receivable.

2.4 Expenditure

Expenditure is recognised once there is a legal or constructive obligation to transfer economic benefit to a third party, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is classified by activity. The costs of each activity are made up of the total of direct costs and shared costs, including support costs involved in undertaking each activity. Direct costs attributable to a single activity are allocated directly to that activity. Shared costs which contribute to more than one activity and support costs which are not attributable to a single activity are apportioned between those activities on a basis consistent with the use of resources. Central staff costs are allocated on the basis of time spent, and depreciation charges allocated on the portion of the asset's use.

2. Accounting policies (continued)

2.4 Expenditure (continued)

Grants payable are charged in the year when the offer is made except in those cases where the offer is conditional, such grants being recognised as expenditure when the conditions attaching are fulfilled. Grants offered subject to conditions which have not been met at the year end are noted as a commitment, but not accrued as expenditure.

Support costs are those costs incurred directly in support of expenditure on the objects of the company. Governance costs are those incurred in connection with administration of the company and compliance with constitutional and statutory requirements.

Costs of generating funds are costs incurred in attracting voluntary income, and those incurred in trading activities that raise funds.

Charitable activities and Governance costs are costs incurred in the company's educational operations, including support costs and costs relating to the governance of the company apportioned to charitable activities.

2.5 Cash flow

The company has taken advantage of the exemption in Financial Reporting Standard No.1 from the requirement to produce a cash flow statement on the grounds that it is a small charitable company.

2.6 Intangible assets and amortisation

Intangible assets costing £500 or more are capitalised and recognised when future economic benefits are probable and the cost or value of the asset can be measured reliably.

Intangible assets are initially recognised at cost. After recognition, under the cost model, intangible assets are measured at cost less any accumulated amortisation and any accumulated impairment losses.

Amortisation is provided on intangible assets at rates calculated to write off the cost of each asset on a straight-line basis over its expected useful life.

The estimated useful lives are as follows:

Amortisation is provided on the following basis:

Website development	-	20 % straight line

2. Accounting policies (continued)

2.7 Tangible fixed assets and depreciation

A review for impairment of a fixed asset is carried out if events or changes in circumstances indicate that the carrying value of any fixed asset may not be recoverable. Shortfalls between the carrying value of fixed assets and their recoverable amounts are recognised as impairments. Impairment losses are recognised in the Statement of Financial Activities incorporating income and expenditure account.

Tangible fixed assets are initially recognised at cost net of accumulated depreciation and any accumulated impairment losses. All costs incurred to bring a tangible fixed asset into its intended working condition should be included in the measurement of cost.

Depreciation is charged so as to allocate the cost of tangible fixed assets less their residual value over their estimated useful lives, on a reducing balance basis.

Depreciation is provided on the following basis:

Office equipment	- 25% reducing balance

2.8 Financial instruments

Debtors
Short term debtors are measured at transaction price, less any impairment.

Creditors
Short term trade creditors are measured at transaction price.

Cash
Cash is represented by cash in hand and deposits with financial institutions repayable without penalty on notice of not more than 24 hours.

There are no complex financial instruments.

2.9 Pensions

The pension costs charges in the financial statements comprise contributions payable by the Charity during the year for a defined contribution personal pension plan for staff. The Charity contributes 1% of eligible pay for those employees enrolled in the plan.

2.10 Fund accounting

General funds are unrestricted funds which are available for use at the discretion of the Trustees in furtherance of the general objectives of the company and which have not been designated for other purposes.

Restricted funds are funds which are to be used in accordance with specific restrictions imposed by donors or which have been raised by the company for particular purposes. The costs of raising and administering such funds are charged against the specific fund. The aim and use of each restricted fund is set out in the notes to the financial statements.

2. Accounting policies (continued)

2.11 Role of Volunteers

The charity relies on the efforts of its volunteers. The value of these volunteers is not incorporated within the accounts.

3. Critical accounting estimates and areas of judgment

Estimates and judgments are continually evaluated and are based on historical experience and other factors, including expectations of future events that are believed to be reasonable under the circumstances.

Critical areas of judgment:

(i) Donations of consulting by Andrew Wakelin
(ii) Donations of conference guest speakers
(iii) Donations of services including printing, graphic design, meeting rooms and consultant attendance of events
(iv) Donation of website development time by Andrew Wakelin.

In accordance with the Charities SORP FRS 102, the charity has valued the benefit it receives from donated services as £47,540 *(2019: £62,320)*. This is based on the open market value of benefits received.

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2020

4. Income from donations and legacies

	Restricted funds 2020 £	Unrestricted funds 2020 £	Total funds 2020 £	*Total funds 2019 £*
Donations	989	9,166	**10,155**	*19,018*
Legacies	-	93	**93**	-
Grants	119,074	6,750	**125,824**	*50,624*
Donations in kind	12,720	34,820	**47,540**	*62,320*
Gift aid	-	1,384	**1,384**	*2,662*
	132,783	52,213	**184,996**	*134,624*
Total 2019	*98,346*	*36,278*	*134,624*	

5. Income from other trading activities

Income from fundraising events

	Restricted funds 2020 £	Unrestricted funds 2020 £	Total funds 2020 £	*Total funds 2019 £*
Fundraising events	11	10,240	**10,251**	*14,362*
Total 2019	*2,192*	*12,170*	*14,362*	

5. Income from other trading activities (continued)

Income from non charitable trading activities

	Restricted funds 2020 £	Unrestricted funds 2020 £	Total funds 2020 £	*Total funds 2019 £*
Conference	-	4,088	**4,088**	*8,835*
Subscriptions	-	1,315	**1,315**	*1,325*
Book Sales	37	33	**70**	*2,168*
Walking courses	4,920	-	**4,920**	*2,738*
Total 2020	4,957	5,436	**10,393**	*15,066*
Total 2019	*3,028*	*12,038*	*15,066*	

6. Investment income

	Unrestricted funds 2020 £	Total funds 2020 £	*Total funds 2019 £*
Investment income	154	**154**	*114*
Total 2019	*114*	*114*	

7. Other incoming resources

	Restricted funds 2020 £	Unrestricted funds 2020 £	Total funds 2020 £	*Total funds 2019 £*
Other income	8	-	**8**	*3,474*
Total 2019	-	*3,474*	*3,474*	

8. Expenditure on raising funds

Costs of raising voluntary income

	Unrestricted funds 2020 £	Total funds 2020 £	*Total funds 2019 £*
Fundraising Expenses	4,152	**4,152**	*5,260*
Total 2019	*5,260*	*5,260*	

9. Analysis of grants

	Grants 2020 £	Total funds 2020 £	*Total funds 2019 £*
Grants	950	**950**	*6,174*
Total 2019	*6,174*	*6,174*	

9. Analysis of grants (continued)

In 2020 no grants were given to institutions *(2019: 1)* and 4 to individuals *(2019: 6)*.

The company has made the following material grants to institutions during the year:

	2020	*2019*
	£	*£*
Name of institution		
Nottingham Trent University	**-**	*5,000*
	-	*5,000*
Other grants to individuals	**950**	*1,174*
	950	*6,174*

10. Analysis of expenditure by activities

	Activities undertaken directly 2020	**Grant funding of activities 2020**	**Support costs 2020**	**Total funds 2020**	*Total funds 2019*
	£	**£**	**£**	**£**	*£*
Charitable activities	115,504	950	96,528	**212,982**	*222,775*
Total 2019	*129,654*	*6,174*	*86,947*	*222,775*	

10. Analysis of expenditure by activities (continued)

Analysis of direct costs

	Total funds 2020 £	*Total funds 2019 £*
Conference	**26,269**	*45,604*
Walking course	**5,395**	*2,219*
Consultancy	**39,540**	*32,070*
Travel and accommodation expenses	**10,059**	*17,074*
Staff costs	**34,241**	*32,687*
	115,504	*129,654*

Analysis of support costs

	Total funds 2020 £	*Total funds 2019 £*
Rent	**2,705**	*4,200*
Office costs	**8,556**	*6,981*
Online services	**644**	*891*
Website and computer costs	**11,110**	*12,387*
Sundry expenses	**3,709**	*3,528*
Subscriptions	**197**	*-*
Insurance	**675**	*698*
Printing, post and stationery	**7,540**	*9,701*
Depreciation - office equipment	**726**	*623*
Amortisation - website development	**4,787**	*4,787*
Accountancy & payroll	**7,922**	*6,751*
Independent examiners fee	**2,321**	*2,325*
Staff costs	**45,636**	*34,075*
	96,528	*86,947*

10. Analysis of expenditure by activities (continued)

Analysis of support costs (continued)

During the year ended 31 March 2020, the company incurred the following Governance costs:

£10,405 (2019 - £9,076) included within the table above.

11. Independent examiner's remuneration

The independent examiner's remuneration amounts to an independent examiner fee of £2,321 (*2019 - £2,235*).

12. Staff costs

	2020	*2019*
	£	*£*
Wages and salaries	**74,741**	*62,731*
Social security costs	**3,925**	*3,332*
Pension costs	**1,211**	*699*
	79,877	*66,762*

The average number of persons employed by the company during the year was as follows:

	2020	*2019*
	No.	*No.*
	2	*2*

The key management personnel of the charity are the Trustees and Development Director. Total employee benefits of key management personnel of the charity were £34,318 (*2019: £34,075*).

No employee received remuneration amounting to more than £60,000 in either year.

13. Trustees' remuneration and expenses

During the year, no Trustees received any remuneration or other benefits *(2019 - £NIL)*.

During the year ended 31 March 2020, no Trustee expenses have been incurred *(2019 - £NIL)*.

14. Intangible assets

	Website development £
Cost	
At 1 April 2019	**23,938**
At 31 March 2020	**23,938**
Amortisation	
At 1 April 2019	**4,787**
Charge for the year	**4,787**
At 31 March 2020	**9,574**
Net book value	
At 31 March 2020	**14,364**
At 31 March 2019	*19,151*

15. Tangible fixed assets

	Office equipment £
Cost or valuation	
At 1 April 2019	**6,333**
Additions	**1,036**
At 31 March 2020	**7,369**
Depreciation	
At 1 April 2019	**4,463**
Charge for the year	**726**
At 31 March 2020	**5,189**
Net book value	
At 31 March 2020	**2,180**
At 31 March 2019	*1,870*

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FOR THE YEAR ENDED 31 MARCH 2020

16. Debtors

	2020 £	*2019 £*
Due within one year		
Trade debtors	**18,205**	-
Prepayments and accrued income	**1,486**	*29,116*
	19,691	*29,116*

17. Creditors: Amounts falling due within one year

	2020 £	*2019 £*
Trade creditors	**318**	-
Other taxation and social security	**891**	*1,073*
Other creditors	**1,123**	*3,534*
Accruals and deferred income	**3,813**	*2,847*
	6,145	*7,454*

18. Statement of funds

Statement of funds - current year

	Balance at 1 April 2019 £	Income £	Expenditure £	Transfers in/out £	Balance at 31 March 2020 £
Unrestricted funds					
General Funds - all funds	39,726	68,043	(92,999)	1,778	16,548
Restricted funds					
Type 2 Pompe	13,820	4,314	(3,479)	-	14,655
Type 5 Mcardle	15,694	10,088	(13,936)	-	11,846
Type 3 Cori	3,379	583	(434)	-	3,528
Type 1 Van Gierke	10,096	5,000	(2,715)	-	12,381
Type 6 Hers Fund	602	-	-	-	602
Hardship Fund	815	-	(700)	-	115
Conferences	13,016	44,819	(45,093)	-	12,742
Medical Advisory Board	2,065	-	-	-	2,065
Specialist Care Advisor	13,479	61,111	(49,145)	-	25,445
Type 0	165	-	-	-	165
Patient Education and Empowerment	26,759	11,844	(8,633)	(1,778)	28,192
	99,890	137,759	(124,135)	(1,778)	111,736
Total of funds	139,616	205,802	(217,134)	-	128,284

18. Statement of funds (continued)

Statement of funds - prior year

	Balance at 1 April 2018 £	Income £	Expenditure £	Transfers in/out £	Balance at 31 March 2019 £
Unrestricted funds					
General Funds - all funds	20,952	64,074	(66,955)	21,655	39,726
Restricted funds					
Type 2 Pompe	14,701	1,307	(2,188)	-	13,820
Type 5 Mcardle	16,428	35,177	(35,911)	-	15,694
Type 3 Cori	7,042	1,568	(5,231)	-	3,379
Type 1 Van Gierke	9,996	100	-	-	10,096
Awards for All	22	-	-	(22)	-
Type 6 Hers Fund	602	-	-	-	602
Hardship Fund	2,026	-	(1,211)	-	815
Conferences	23,911	40,932	(51,827)	-	13,016
Medical Advisory Board	2,065	-	-	-	2,065
Specialist Care Advisor	60,148	13,056	(59,725)	-	13,479
Type 0	165	-	-	-	165
Website Redevelopment	24,905	-	(3,272)	(21,633)	-
Patient Education and Empowerment	17,048	11,426	(1,715)	-	26,759
	179,059	103,566	(161,080)	(21,655)	99,890
Total of funds	200,011	167,640	(228,035)	-	139,616

19. Summary of funds

Summary of funds - current year

	Balance at 1 April 2019 £	Income £	Expenditure £	Transfers in/out £	Balance at 31 March 2020 £
General funds	**39,726**	**68,043**	**(92,999)**	**1,778**	**16,548**
Restricted funds	**99,890**	**137,759**	**(124,135)**	**(1,778)**	**111,736**
	139,616	**205,802**	**(217,134)**	**-**	**128,284**

Summary of funds - prior year

	Balance at 1 April 2018 £	*Income £*	*Expenditure £*	*Transfers in/out £*	*Balance at 31 March 2019 £*
General funds	*20,952*	*64,074*	*(66,955)*	*21,655*	*39,726*
Restricted funds	*179,059*	*103,566*	*(161,080)*	*(21,655)*	*99,890*
	200,011	*167,640*	*(228,035)*	*-*	*139,616*

19. Summary of funds (continued)

Restricted Funds

Type 2 Pompe's

Supporting GSD Type 2, Pompe.

Type 5 McArdles

Supporting GSD Type 5, McArdle.

Type 3 Cori

Supporting GSD Type 3, Cori.

Type 1 Von Gierke

Supporting GSD Type 1, Von Gierke.

Awards for All

The Big Lottery - production of literature on all GSD's.

Type 6 Hers Fund

Supporting GSD Type 6, Hers.

Hardship Fund

Supporting patients and families suffering hardship.

Conferences

Supporting AGSD-UK Annual conference.

Medical Advisory Board

Supporting meetings of AGSD-UK Medical Advisors.

Specialist Care Advisor

Supporting the provision of a Pompe patient support worker.

Type 0

Supporting GSD Type 0.

Website Redevelopment Fund

Supporting the redevelopment of the charity's website

19. Summary of funds (continued)

Patient Education and Empowerment

Supporting patients and families by providing family days.

Transfer between funds

The transfer out of the Patient Education and Empowerment Fund represents event costs misallocated to general funds in prior years. These amounts have been transferred to unrestricted funds.

20. Analysis of net assets between funds

Analysis of net assets between funds - current period

	Restricted funds 2020 £	Unrestricted funds 2020 £	Total funds 2020 £
Tangible fixed assets	-	2,180	**2,180**
Intangible fixed assets	1,473	12,891	**14,364**
Current assets	158,531	(40,646)	**117,885**
Creditors due within one year	(5,629)	(516)	**(6,145)**
Difference	(42,639)	42,639	**-**
Total	111,736	16,548	**128,284**

Analysis of net assets between funds - prior period

	Restricted funds 2019 £	*Unrestricted funds 2019 £*	*Total funds 2019 £*
Tangible fixed assets	-	1,870	*1,870*
Intangible fixed assets	-	19,151	*19,151*
Current assets	101,475	24,574	*126,049*
Creditors due within one year	(1,585)	(5,869)	*(7,454)*
Total	99,890	39,726	*139,616*

21. Pension commitments

The Charity operates a defined contribution pension scheme. The assets of the scheme are held separately from those of the Charity in independently administered funds. The pension cost shown in note 12 represents the contributions payable by the Charity to these funds.

22. Operating lease commitments

At 31 March 2020 the company had commitments to make future minimum lease payments under non-cancellable operating leases as follows:

	2020	*2019*
	£	*£*
Land and buildings		
Not later than 1 year	**312**	*4,200*

23. Related party transactions

There were no related party transactions for the year ended 31 March 2020.