

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 2019



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

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ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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**REFERENCE AND ADMINISTRATIVE DETAILS OF THE COMPANY, ITS TRUSTEES AND ADVISERS
FOR THE YEAR ENDED 31 MARCH 2019**

Trustees

Jayesh Pindolia
Michael Porter (resigned 19 January 2019)
Stuart Alderson
Nicholas Jones
Ailsa Arthur
Jane Mary Guy
Heneage Legge-Bourke (resigned 28 February 2019)
Robert Seaborne

Company registered number

06981121

Charity registered number

1132271

Registered office

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

Company secretary

Neil Bradbury (appointed 16 August 2019)

Chief executive officer

Neil Bradbury (appointed 1 August 2019)

Key management team

Allan Muir, Charity Director (resigned 13 September 2019)

Independent examiner

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

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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TRUSTEES' REPORT
FOR THE YEAR ENDED 31 MARCH 2019

The Trustees present their annual report together with the financial statements of the company for the 1 April 2018 to 31 March 2019. The Trustees confirm that the Annual Report and financial statements of the company comply with the current statutory requirements, the requirements of the 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 (FRS 102) (effective 1 January 2015).

Since the company qualifies as small under section 383, the strategic report required of medium and large companies under The Companies Act 2006 (Strategic Report and Director's Report) Regulations 2013 is not required.

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 FOR ACHIEVING 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.

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.

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TRUSTEES' REPORT (continued)
FOR THE YEAR ENDED 31 MARCH 2019

Achievements and performance

a. REVIEW OF ACTIVITIES

2018-19 was a challenging year for the charity as we implemented a new business plan and reorganised the organisation. The financial year we operate in is different to that of our main funders, who operate on a calendar year basis. As a result, income which would usually show in this years accounts will fall in 2019-20. There has been no change to our sustainable income outlook during the year. During the year the trustee board met three times and in addition a number of trustee board sub committees met throughout the year.

In addition to income generation the major areas of focus for the year have been: further strengthening our policies and procedures, working with a professional systems company to update our IT infrastructure, developing a new website, succession planning for key roles, increasing our publication library and broadening our outreach services through the work of our Specialist Care Advisor.

Andrew Wakelin, GSD5 co-ordinator, lead the development of our new website and delivered a complete redesign and restructure for the website. He gave several months of work as a volunteer.

Currently we are getting an average of 2,900 visitors per month, with over 7,500 page views. 35% of users are from the UK, 29% from the US and the rest from all around the world. Smartphone usage is growing, with now 47% of users on that platform, another 47% on desktop computers and 6% on laptops. In the most recent month, apart from the homepage, the most visited page was our news story on a Netflix documentary mentioning muscle GSDs.

Our 2018 conference was held at the Wyboston Lakes Centre near Milton Keynes and was well attended. We welcomed a total of 180 delegates including 49 affected by GSD members. Our crèche was provided by the Bulwell Toy Library for the second year running.

We had colourful displays at the AGSD UK Teens Project, AGSD UK Kids Camp, Hope the GSD2 Sloth Mascot, Mangar Camel Floor Lifting Device event and with Accuvein.

Feedback on the success of the conference remains fairly consistent over the year. The primary reason people attend the conference is for social contact, making friends and networking. Secondly, delegates want to be updated on the latest research, new learning and improving knowledge. Mentioned by some, and also very important, are the contacts they make with medical professionals. Interestingly a lot of people mentioned a wide variety of benefits.

The trustee board met three times in June 2018, October 2018 and January 2019. In addition a trustee training day was held in June 2018. A number of sub-committee meetings were also held throughout the year.

Allan Muir, who had been running the day-to-day operations of AGSD-UK since 2010, left the organisation in September 2019 to pursue his own business interests. Allan who has been closely involved with the charity for over 20 years, has helped AGSD-UK to develop and grow over that time and provided invaluable support to the UK and international Pompe community. The trustees would like to place on record their thanks and gratitude for Allan's many years of dedication to the UK GSD community.

Our new website was formally launched in January 2019 and I am sure you will agree it is a significant improvement when compared to our old clunky text-based site. The launch would not have been possible without a massive amount of input and effort from our McArdle co-ordinator, Andrew Wakelin.

One of the major successes of our Specialist Care Advisor role has been to provide practical and emotional support to those GSD sufferers going through the government mandated benefits move from Disability Living Allowance (DLA) to Personal Independence Payment (PIP). The process for claimants is very challenging and anxiety inducing and I am pleased to report that Jane Lewthwaite has supported 66 PIP submissions and

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TRUSTEES' REPORT (continued)
FOR THE YEAR ENDED 31 MARCH 2019

around a further 40 submissions for Employment Support Allowance and Carers Allowance. Jane has also been involved in 3 PIP appeals, all of which have been successful. Providing advocacy work such as this for the UK GSD community is invaluable in meeting the needs of our sufferers and their families/careers.

As well as hosting our annual AGSD-UK conference in Wyboston and a number of regional meetings, the charity was represented at the European Orphan Drug Congress in Barcelona by Ailsa Arthur, Jane Lewthwaite, Jason McMillan and Allan Muir, by Rob Seaborne and Allan Muir at the World Symposium on Lysosomal Storage Disorders in Florida and by Jane Lewthwaite at the Genetic Alliance Annual Meeting in London. As previously reported attendance at such events contributes to our store of knowledge regarding emerging developments in the field of GSD diseases as well as supporting the 'vision' of AGSD-UK in being the primary and central focus for information and support, driving positive change for all people affected by Glycogen Storage Disease.

We now have 320 people diagnosed with McArdle disease in the UK, of which about 240 attend the national McArdle disease clinic in London. We support the clinic in a number of ways. The clinic is now organised so that there can be a one hour patient group meeting around lunchtime. This is especially helpful for newly diagnosed patients to meet those with experience of the condition. Our members participated in a number of trials in London and Copenhagen.

In the summer of 2018 we ran our walking course in the Brecon Beacons National Park for the first time, having previously been in the Snowdonia and Pembrokeshire National Parks. Both the main course and the Children & Parents event were located in self-catering accommodation near Hay on Wye. Several of the walks were highlights, including a circuit over Hay Bluff, one that included going behind the cascading water of a waterfall, and a large group summited Pen y Fan, the highest mountain in southern Britain at 2,907 ft. A remarkable achievement for a disparate group of people with a muscle GSD. Both events were great successes with participants coming from England, Scotland, Wales, Ireland, France, Germany, Belgium, the USA and New Zealand.

We supported the continuing development of the international body for muscle GSDs – lamGSD, including helping to host an international workshop on the future of nutrition for McArdle disease, held in London in November. We also supported the German self-help group SHG at their annual conference, including running a few hours practical workshop on the lines of our walking courses.

Jane Lewthwaite has been our Specialist Care Advisor for three years.

The Pompe SCA is tasked with these aims:

- To make a positive difference to the lives of people affected by Pompe disease through providing non-clinical advice, support and information to patients, parents and care-givers.
- To enable people affected by Pompe Disease to access a range of non-clinical services with the object of enhancing and improving their quality of life.
- To provide advice and support for all referred individuals and families on a broad range of quality of life issues including; benefits, housing, finance, aids, mobility and travel, grants, counselling, access, safety, education and employment.
- To ensure people who need the service are not excluded.

Most support is provided via phone, email and Facebook with some home or hospitals visits. The Care Advisor promotes opportunities for raising awareness of the patient voice and of GSD as a rare condition. Jane administrates The Pompe Support Team, which is vital in providing speakers for events, industry meetings and conferences. In March the team had one-day training in Health Economics provided by Francis Pang.

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TRUSTEES' REPORT (continued)
FOR THE YEAR ENDED 31 MARCH 2019

We were successful in gaining grants for individual people in need

- Nine individual £100 grants from Campbell Burns Metabolic Trust
- Eight In-house individual grants total £1,630
- £560 towards a family holiday from the Sandcastle Trust
- A £500 grant towards white goods R.E.A.C.T
- Two applications made to Merlin's Magic Wand for trips
- One application made to Short Breaks for children

Family Days

Hospitals are invited to collaborate with the SCA, who arranges the day, including food, entertainment, craft, promotion and volunteers. During the event the priority is to promote AGSD UK and gather registrations. Every individual is followed up with phone calls and information such as leaflets or tailored advice. News items are submitted for the website. Feedback is gathered. Funded by a grant from St James Place.

- Great Ormond Street Children's Hospital
- Evelina Children's Hospital
- Birmingham Children's Hospital

International Pompe Day April 15th

A key aim was to deliver regional events for people with GSD2. For the last four years PST has been supported to deliver a weekend social but this is always in the Midlands and attended by more or less the same small group. Events were planned in Stoke [a weekend social run by Ben Parker], Swansea and Southampton.

GSD Kids Camp

September 2018 Kids Camp was provided by Over the Wall and funded by Shire Pharmaceuticals. Benefits for children were extensive. Over the Wall provide a very high quality experience with attendant medical staff. However, their administration had issues and three GSD families who wished to attend missed the event.

The Cori Action team collated and produced a "Top Tips" booklet for Cori disease. Thanks go to Dr Elaine Murphy at The National Hospital for Neurology and Neurosurgery, London for her help with reviewing content. The Pompe Support Team members produced a recipe book called "Be Inspired to Eat Well". It is not a recipe book for GSD, but suggestions for trying new and different healthy alternatives. AGSD UK produced a fundraising calendar, collated via a photographic competition organised by Gemma Seyfang.

We take this opportunity to thank all our wonderful fundraisers.

We are grateful to all our supporters who have used the following events to raise sponsorship money:

- London Marathon
- London Vitality 10k run
- Prudential Ride London-Surrey cycling events
- Project JOGLE cycle from John O Groats to Land's End lead by the daughter of member Joan Wright

We thank everyone who contributed by organising local events such as a bake sales or book stalls and especially those who requested donations to AGSD-UK in lieu of birthday presents.

Major donors who support our work are generally biotechnology or specialist nutrition companies:-

- Amicus Therapeutics
- Audentes Therapeutics
- Sanofi-Genzyme Ltd
- Valerion Therapeutics
- Vitaflo International

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TRUSTEES' REPORT (continued) FOR THE YEAR ENDED 31 MARCH 2019

Trusts and Foundations who supported us and our members throughout the year:-

- St James Place Foundation
- Campbell Burns Metabolic Trust
- Buttle UK
- Sandcastle Trust

We are proud of the services we provide to people with GSD and the difference we make to peoples lives. Our massive volunteer base relative to the size of the charity and the GSD population in the UK means AGSD UK is at the forefront of rare disease patient charities.

As always the charity is extremely grateful for the continuing support of our donors, fund raisers, grant makers and various sponsors from pharmaceutical, nutrition, and biotechnology industries. Their efforts on our behalf enables the charity to maintain its support to all people affected by GSD in the UK.

Financial review

a. GOING CONCERN

The company has cash resources and has no requirement for external funding. At the date of signing the accounts the free reserves stand at £18,705. 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. INVESTMENT POLICY AND PERFORMANCE

The Association holds its 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.

c. RESERVES POLICY

The Association holds some funds that are restricted in expenditure in support of particular GSD Types and other projects (see note 19). The total amount of restricted funds held at the year-end were £99,890. The general reserves are used to support the on going activities of the Association. The unrestricted general reserve now stands at £39,726 which is an increase from the previous year (£20,952). The free reserves comprises unrestricted funds less fixed assets attributed to restricted funds was £18,705. 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 free reserves. The trustees have agreed to adopt a reserve policy that seeks to carry forward a free reserves figure that is no greater than 25% of total in year expenditure. Based on the 2018 accounts this would amount to £15,424.

Structure, governance and management

a. CONSTITUTION

The company is registered as a charitable company limited by guarantee and was set up 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".

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TRUSTEES' REPORT (continued)
FOR THE YEAR ENDED 31 MARCH 2019

b. METHOD 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. REMUNERATION OF KEY MANAGEMENT PERSONNEL

The company currently has two permanent members of staff – Charity Director and Specialist Care Advisor. The remuneration for both posts was benchmarked at or below market rate prior to appointment and is reviewed by Trustees annually.

d. ORGANISATIONAL STRUCTURE AND DECISION MAKING

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 are supported by the Development Director. They meet as a group three times a year for peer support and development in their role.

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.

Plans for future periods

a. FUTURE DEVELOPMENTS

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

This report was approved by the Trustees, on 6/10/19 and signed on their behalf by:

Nicholas Jones
Trustee



ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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**INDEPENDENT EXAMINER'S REPORT
FOR THE YEAR ENDED 31 MARCH 2019**

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 2019.

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.

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.

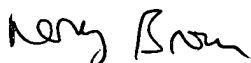
INDEPENDENT EXAMINER'S STATEMENT

I have completed my examination. I can 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.

Signed:



Dated: 12/12/19

Kerry Brown FCA

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

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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**STATEMENT OF FINANCIAL ACTIVITIES INCORPORATING INCOME AND EXPENDITURE ACCOUNT
FOR THE YEAR ENDED 31 MARCH 2019**

	Note	Restricted funds 2019 £	Unrestricted funds 2019 £	Total funds 2019 £	Total funds 2018 £
INCOME FROM:					
Donations and grants	2	98,346	36,278	134,624	249,316
Other trading activities	3,4	5,220	24,208	29,428	49,683
Investments	5	-	114	114	26
Other income	6	-	3,474	3,474	400
TOTAL INCOME		103,566	64,074	167,640	299,425
EXPENDITURE ON:					
Raising funds	4,7	-	5,260	5,260	3,064
Charitable activities	8,10	161,080	61,695	222,775	229,472
TOTAL EXPENDITURE		161,080	66,955	228,035	232,536
NET INCOME / (EXPENDITURE) BEFORE TRANSFERS		(57,514)	(2,881)	(60,395)	66,889
Transfers between Funds	19	(21,655)	21,655	-	-
NET INCOME / (EXPENDITURE) BEFORE OTHER RECOGNISED GAINS AND LOSSES		(79,169)	18,774	(60,395)	66,889
NET MOVEMENT IN FUNDS		(79,169)	18,774	(60,395)	66,889
RECONCILIATION OF FUNDS:					
Total funds brought forward		179,059	20,952	200,011	133,122
TOTAL FUNDS CARRIED FORWARD		99,890	39,726	139,616	200,011

The notes on pages 11 to 26 form part of these financial statements.

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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REGISTERED NUMBER: 06981121

BALANCE SHEET
AS AT 31 MARCH 2019

	Note	£	2019	£	£	2018	£
FIXED ASSETS							
Intangible assets	14			19,151			8,808
Tangible assets	15			1,870			2,034
				<u>21,021</u>			<u>10,842</u>
CURRENT ASSETS							
Debtors	16	29,116			7,415		
Cash at bank and in hand		96,933			186,284		
				<u>126,049</u>		<u>193,699</u>	
CREDITORS: amounts falling due within one year	17	(7,454)			(4,530)		
NET CURRENT ASSETS				<u>118,595</u>			<u>189,169</u>
NET ASSETS				<u>139,616</u>			<u>200,011</u>
CHARITY FUNDS							
Restricted funds	19			99,890			179,059
Unrestricted funds	19			39,726			20,952
TOTAL FUNDS				<u>139,616</u>			<u>200,011</u>

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

The Trustees consider that the company is entitled to exemption from the requirement to have an audit under the provisions of section 477 of the Companies Act 2006 ("the Act") and members have not required the company to obtain an audit for the year in question in accordance with section 476 of the Act.

The Trustees acknowledge their responsibilities for complying with the requirements of the Companies Act 2006 with respect to accounting records and the preparation of financial statements.

The financial statements were approved and authorised for issue by the Trustees on 6/10/19 and signed on their behalf, by:



Nicholas Jones

The notes on pages 11 to 26 form part of these financial statements.

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NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2019

1. ACCOUNTING POLICIES

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.

1.2 Basis of preparation of financial statements

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015) - (Charities SORP (FRS 102)), 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.

1.3 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.

1.4 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.

1.5 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.

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**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2019**

1. ACCOUNTING POLICIES (continued)

1.6 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.

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 on the company's educational operations, including support costs and costs relating to the governance of the company apportioned to charitable activities.

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.

1.7 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.

1.8 Intangible fixed 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 and are subsequently measured at cost net of amortisation and any provision for impairment

Amortisation is provided on intangible fixed assets at rates calculated to write off the cost of each asset, less their estimated residual value, over their expected useful lives on the following bases:

Website development	-	Over 5 years
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**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2019**

1. ACCOUNTING POLICIES (continued)

1.9 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 carried at cost, net of depreciation and any provision for impairment. Depreciation is provided at rates calculated to write off the cost of fixed assets, less their estimated residual value, over their expected useful lives on the following bases:

Office equipment	- 25% Reducing balance
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1.10 Pensions

The pension costs charged 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.

1.11 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.

1.12 Role of Volunteers

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

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**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2019**

1. ACCOUNTING POLICIES (continued)

1.13 Significant accounting estimates and areas of judgement

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) Donation 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 £62,320 (2018: £72,310). This is based on the open market value of the benefits received.

2. INCOME FROM DONATIONS AND LEGACIES

	Restricted funds 2019 £	Unrestricted funds 2019 £	Total funds 2019 £	Total funds 2018 £
Donations	8,007	11,011	19,018	15,365
Legacies	-	-	-	2,000
Grants	43,369	7,255	50,624	154,935
Donations in kind	46,970	15,350	62,320	72,310
Gift aid	-	2,662	2,662	4,706
Total donations and legacies	98,346	36,278	134,624	249,316
Total 2018	200,512	48,804	249,316	

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3. ACTIVITIES TO GENERATE FUNDS

	Restricted funds 2019 £	Unrestricted funds 2019 £	Total funds 2019 £	Total funds 2018 £
Fundraising events	2,192	12,170	14,362	23,965
	<u>2,192</u>	<u>12,170</u>	<u>14,362</u>	<u>23,965</u>
<i>Total 2018</i>	<u>3,821</u>	<u>20,144</u>	<u>23,965</u>	

4. INCOMING RESOURCES FROM CHARITABLE ACTIVITIES

	Restricted funds 2019 £	Unrestricted funds 2019 £	Total funds 2019 £	Total funds 2018 £
Conference	-	8,835	8,835	20,942
Subscriptions	-	1,325	1,325	980
Book sales	290	1,878	2,168	1,126
Walking courses	2,738	-	2,738	2,670
	<u>3,028</u>	<u>12,038</u>	<u>15,066</u>	<u>25,718</u>
Incoming resources from charitable activities	<u>3,028</u>	<u>12,038</u>	<u>15,066</u>	<u>25,718</u>

In 2018, of the total income from charitable activities, £980 was to unrestricted funds and £24,738 was to restricted funds.

5. INVESTMENT INCOME

	Restricted funds 2019 £	Unrestricted funds 2019 £	Total funds 2019 £	Total funds 2018 £
Investment income	-	114	114	26
	<u>-</u>	<u>114</u>	<u>114</u>	<u>26</u>
<i>Total 2018</i>	<u>-</u>	<u>26</u>	<u>26</u>	

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6. OTHER INCOMING RESOURCES

	Restricted funds 2019 £	Unrestricted funds 2019 £	Total funds 2019 £	Total funds 2018 £
Other income	-	3,474	3,474	400
<i>Total 2018</i>	-	400	400	

7. FUNDRAISING TRADING

	Restricted funds 2019 £	Unrestricted funds 2019 £	Total funds 2019 £	Total funds 2018 £
Fundraising expenses	-	5,260	5,260	3,064
<i>Total 2018</i>	-	3,064	3,064	

8. DIRECT COSTS

	Charitable activities £	Total 2019 £	Total 2018 £
Conference	45,604	45,604	62,740
Walking courses	2,219	2,219	4,134
Consultancy	32,070	32,070	39,500
Travel and accommodation expenses	17,074	17,074	12,293
Wages and salaries	29,131	29,131	28,055
National insurance	2,857	2,857	2,746
Pension cost	699	699	281
	129,654	129,654	149,749
<i>Total 2018</i>	149,749	149,749	

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9. ANALYSIS OF GRANTS

	Grants 2019 £	Total 2019 £	Total 2018 £
Grants	6,174	6,174	3,782
<i>Total 2018</i>	<i>3,782</i>	<i>3,782</i>	

In 2019 one grant was made to an institution (2018: Nil) and 6 to individuals (2018: 6).

Grants to institutions were as follows:

	2019 £	2018 £
Nottingham Trent University	5,000	-

10. SUPPORT COSTS

	Charitable activities £	Total 2019 £	Total 2018 £
Rent	4,200	4,200	4,200
Office costs	6,981	6,981	2,698
Online services	891	891	1,586
Website and computer costs	12,387	12,387	10,039
Sundry expenses	3,528	3,528	2,736
Insurance	698	698	559
Printing, postage and stationery	9,701	9,701	12,247
Depreciation - office equipment	623	623	678
Amortisation - website development	4,787	4,787	-
Consultancy	-	-	1,295
Accountancy & payroll	6,751	6,751	3,558
Independent examiners fee	2,325	2,325	2,235
Wages and salaries	33,600	33,600	33,600
National Insurance	475	475	510
	86,947	86,947	75,941
<i>Total 2018</i>	<i>75,941</i>	<i>75,941</i>	

During the year ended 31 March 2019, the company incurred the following Governance costs:
£9,076 (2018 - £7,088) included within the table above.

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11. NET INCOME/(EXPENDITURE)

This is stated after charging:

	2019 £	2018 £
Depreciation of tangible fixed assets: - owned by the charity	623	678
Amortisation of intangible fixed assets	4,787	-
	<u>5,410</u>	<u>678</u>

Trustees received remuneration amounting to £NIL in the current year (2018 - £NIL).

During the year, no Trustees received any benefits in kind (2018 - £NIL).

During the year, 1 Trustees (2018 - 3) received reimbursement of expenses of £78 (2018 - £526) for travel.

12. INDEPENDENT EXAMINER'S REMUNERATION

The Independent Examiner's remuneration amounts to an Independent Examination fee of £2,235 (2018 - £2,190).

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13. STAFF COSTS

Staff costs were as follows:

	2019 £	2018 £
Wages and salaries	62,731	61,655
Social security costs	3,332	3,256
Pension costs	699	281
	<u>66,762</u>	<u>65,192</u>

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

	2019 No.	2018 No.
	2	2

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

The key management personnel of the charity are the Trustees and Development Director. Total employee benefits of key management personnel of the charity were £34,075 (2018: £34,110).

14. INTANGIBLE FIXED ASSETS

	Website development £
Cost	
At 1 April 2018	8,808
Additions	15,130
At 31 March 2019	<u>23,938</u>
Amortisation	
At 1 April 2018	-
Charge for the year	4,787
At 31 March 2019	<u>4,787</u>
Carrying amount	
At 31 March 2019	<u>19,151</u>
At 31 March 2018	<u>8,808</u>

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15. TANGIBLE FIXED ASSETS

	Office equipment £
Cost	
At 1 April 2018	5,874
Additions	459
At 31 March 2019	<u>6,333</u>
Depreciation	
At 1 April 2018	3,840
Charge for the year	623
At 31 March 2019	<u>4,463</u>
Net book value	
At 31 March 2019	<u>1,870</u>
At 31 March 2018	<u>2,034</u>

16. DEBTORS

	2019 £	2018 £
Prepayments and accrued income	<u>29,116</u>	<u>7,415</u>

17. CREDITORS: Amounts falling due within one year

	2019 £	2018 £
Other taxation and social security	1,073	545
Other creditors	3,534	1,519
Accruals and deferred income	2,847	2,466
	<u>7,454</u>	<u>4,530</u>

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18. FINANCIAL INSTRUMENTS

	2019	2018
	£	£
Financial assets measured at amortised cost	120,850	186,284
Financial liabilities measured at amortised cost	7,454	4,530

Financial assets measured at amortised cost comprise cash at bank and accrued income.

Financial liabilities measured at amortised cost comprise PAYE, accruals and other creditors

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**NOTES TO THE FINANCIAL STATEMENTS
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19. STATEMENT OF FUNDS

STATEMENT OF FUNDS - CURRENT 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's	14,701	1,307	(2,188)	-	13,820
Type 5 McArdles	16,428	35,177	(35,911)	-	15,694
Type 3 Cori	7,042	1,568	(5,231)	-	3,379
Type 1 Von 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 Fund	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

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19. STATEMENT OF FUNDS (continued)

STATEMENT OF FUNDS - PRIOR YEAR

	<i>Balance at 1 April 2017</i>	<i>Income</i>	<i>Expenditure</i>	<i>Transfers in/out</i>	<i>Balance at 31 March 2018</i>
	£	£	£	£	£
General Funds - all funds	4,975	70,354	(54,377)	-	20,952
Restricted funds					
Type 2 Pompe's	15,912	4,298	(5,509)	-	14,701
Type 5 McArdles	17,811	43,543	(44,926)	-	16,428
Type 3 Cori	7,010	198	(166)	-	7,042
Type 1 Von Gierke	6,147	3,849	-	-	9,996
Awards for All	22	-	-	-	22
Type 6 Hers Fund	602	-	-	-	602
Hardship fund	3,434	1,300	(2,708)	-	2,026
Conferences	77	103,322	(79,488)	-	23,911
Medical Advisory Board	2,065	-	-	-	2,065
Specialist Care Advisor	47,875	57,238	(44,965)	-	60,148
Type 0	165	-	-	-	165
Website Redevelopment Fund	24,905	-	-	-	24,905
Patient Education and Empowerment	2,122	15,323	(397)	-	17,048
	<u>128,147</u>	<u>229,071</u>	<u>(178,159)</u>	<u>-</u>	<u>179,059</u>

SUMMARY OF FUNDS - CURRENT YEAR

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

SUMMARY OF FUNDS - PRIOR YEAR

	<i>Balance at 1 April 2017</i>	<i>Income</i>	<i>Expenditure</i>	<i>Balance at 31 March 2018</i>
	£	£	£	£
General funds	4,975	70,354	(54,377)	20,952
Restricted funds	128,147	229,071	(178,159)	179,059
	<u>133,122</u>	<u>299,425</u>	<u>(232,536)</u>	<u>200,011</u>

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NOTES TO THE FINANCIAL STATEMENTS
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19. STATEMENT 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

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**NOTES TO THE FINANCIAL STATEMENTS
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19. STATEMENT OF FUNDS (continued)

Patient Education and Empowerment

Supporting patients and families by providing family days.

Transfers between funds

The transfers out of the Awards for All Funds represents the unspent amount of the funding stream which has ceased. There are no obligations in place to return any unspent amounts and so the funds were transferred to unrestricted funds.

The Website Redevelopment was treated as an unrestricted intangible asset on balance sheet. The full amount of the awarded grant has been spent on the project therefore the remaining balance on the fund has been transferred to unrestricted funds.

20. ANALYSIS OF NET ASSETS BETWEEN FUNDS

ANALYSIS OF NET ASSETS BETWEEN FUNDS - CURRENT YEAR

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

ANALYSIS OF NET ASSETS BETWEEN FUNDS - PRIOR YEAR

	Restricted funds 2018 £	Unrestricted funds 2018 £	Total funds 2018 £
Intangible fixed assets	8,808	-	8,808
Tangible fixed assets	-	2,034	2,034
Current assets	171,470	22,229	193,699
Creditors due within one year	(1,219)	(3,311)	(4,530)
	179,059	20,952	200,011

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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 13 represent the contributions payable by the Charity to these funds.

22. OPERATING LEASE COMMITMENTS

At 31 March 2019 the total of the Charity's future minimum lease payments under non-cancellable operating leases was:

	Land and buildings	
	2019	2018
	£	£
Amounts payable:		
Within 1 year	4,200	4,200

23. RELATED PARTY TRANSACTIONS

There were no related party transactions for the year ended 31 March 2019.