

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

UNAUDITED

TRUSTEES' REPORT AND FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2022

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

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

**REFERENCE AND ADMINISTRATIVE DETAILS OF THE COMPANY, ITS TRUSTEES AND ADVISERS
FOR THE YEAR ENDED 31 MARCH 2022**

Trustees

Jayesh Pindolia (resigned 4 April 2022)
Nicholas Jones
Ailsa Arthur
Robert Seaborne (resigned 31 July 2021)
Sarah Chikhani
Rachel Thomas
Dr Emilie Florence Osborne (appointed 1 May 2021)

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

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

TRUSTEES' REPORT
FOR THE YEAR ENDED 31 MARCH 2022

The Trustees present their annual report together with the financial statements of the company for the 1 April 2021 to 31 March 2022. 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.

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2022

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.

e. Research, Policy and service influence

During the year AGSD-UK was active in working with the industry, agency and professional partners to help to shape and recruit to a range of research studies.

We continued to be involved in important partnerships such as the LSD Collaborative whose influence helped to achieve the strong emphasis on speeding diagnosis and facilitating newborn screening in the Rare Disease Action plan.

In order to drive improvements in care we took part in the meetings with specialist hospital teams, contributed to the NHS LSD patient experience work-stream and facilitated multi-disciplinary meetings for specialist professionals to enable them to share experiences and evidence for good practice.

As stakeholders, we gathered and submitted evidence to the NICE technology appraisal for Avaglucoasidae Alfa as well as nominating and supporting patient experts. As a result of this process NICE gave approval for the therapy in August 2022.

We also submitted evidence to the NICE methods review consultation, commenting on proposed changes to the criteria for Highly Specialised Technology Assessments. We emphasised the importance of considering a broad range of evidence when assessing treatments for very rare conditions and the particular inequalities faced by those with rare conditions that need to be taken into account. We continue to work closely with other partners in the rare conditions field as we push for speedy access to effective treatments.

Achievements and performance

a. Review of activities

Information and Support

Whilst the uncertainty of Covid had an ongoing impact on our ability to plan face to face activities during this time, we continued to offer information, support and services remotely. As in the previous year, a successful online winter season was held. This provided opportunities for updates on treatment and research from leading professional and industry partners, as well as for online social events and sharing of experiences, helpful tips and inspirational stories among community members. The season comprised 10 community events and 30 presentations, which attracted a total of 2,487 views and very positive feedback:

"Thanks for hosting the Zoom meeting, it was very helpful to get a sense of the situation for others. I am happy to now know a few people out there!"

"Thank you for arranging yesterday's Zoom get-together. It was very reassuring to hear so many similar experiences."

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TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2022

Achievements and performance (continued)

"I am watching all the videos. I think they are so useful. It is important that we with rare diseases share information both clinical and anecdotal about our conditions."

Overall our website, with its range of news and information for people with every GSD was visited 47,611 times whilst our regular Glisten magazine, packed with practical information, research updates and personal stories across the GSD spectrum reached 1500 individuals and organisations on and off line.

Our care advisor and benefits service continued to provide wide-ranging support, covering issues such as housing and home adaptations, support with special educational needs, adjustments at work, navigating health and social care services and accessing grants and welfare benefits.

This involved liaison with multiple agencies across education, health, social care, government departments and the voluntary sector, as well as intensive work with families with complex needs.

The service was highly successful in securing additional support and enabling people to receive the benefits they were entitled to, including reversing earlier decisions through the appeals process.

Families reported outcomes such as increased wellbeing, greater independence, reduced isolation and less financial anxiety as a result of interventions that, for example, facilitated access to counselling and emotional support, community transport, housing adaptations, enhanced social care packages as well as welfare benefits. They frequently expressed their appreciation for the staff involved:

"You have been so supportive and helpful right from the start till now."

"I would like to say a massive thanks to the full AGSD team for all their efforts..."

Finance, fundraising and future plans

Over the course of the year the community continued to benefit from the dedication of our volunteers, who were active in fundraising, sharing information on social media, organising events, contributing to research and providing peer support.

In our small rare condition charity the efforts of volunteers are crucial in bringing in funds and adding capacity, with their benefit in kind contribution representing around £60,000 each year.

This is hugely important in a tightening financial environment, compounded by inflationary pressures. In this context we continue to manage costs stringently, keeping our overheads to a bare minimum through the employment of a part-time CEO and small freelance support team who are all home based. Delays in funding decisions and processes experienced in this financial year mean that moving forward we are determined to obtain early funding commitments to support our programme for the year ahead.

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2022

Financial review

a. Going concern

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 £23,462 which is a decrease from the previous year (£27,301). The trustees' future focus will be on increasing income while tightly managing costs. The total restricted funds is now £72,936 which is fairly consistent from the prior year (£82,196).

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 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.

Structure, governance and management

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.

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TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2022

Structure, governance and management (continued)

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 Chief Executive 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 part-time permanent member of staff – the Chief Executive, with four part-time freelance team members.

The remuneration for key management posts was benchmarked at or below market rate prior to appointment and is reviewed by Trustees annually.

e. Financial risk management

The Trustees have assessed the major risks to which the company is exposed, in particular those related to the operations and finances of the company, and are satisfied that systems and procedures are in place to mitigate exposure to the major risks.

f. 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.

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2022

Plans for future periods

The development of a clear 3 year strategy was seen as an important platform for securing project and trust funding as well as helping to ensure we target our limited resources to deliver the greatest possible impact. Work moved forward with this in the latter part of the financial year with a listening exercise to determine the things community members felt would most improve their lives with the condition. Three clear themes emerged, which form the framework for the strategy:

- Support across the community
- Help with living well
- Better treatments and service access

Clear goals and outcome measures have been developed for each of these themes, along with an additional supporting theme of being a strong and effective organisation.

An organisational plan to achieve these over the next three years is now in place and work to deliver this is moving forward in the current financial year. Progress already being seen, in terms of levels of community support, involvement in research and evidence building and collaboration with professionals.

We are extremely grateful to our industry and trust partners including Amicus, Astellas/Audentes, AvroBio, Beam, Edward Gostling Foundation, FMR Global Health, Sangomo, Sanofi Genzyme, Spark Therapeutics, Ultragenyx and Vitaflo for supporting our programme of activities and for working with us for the benefit of people affected.

Our heartfelt thanks go to all those individuals and organisational partners who have supported our mission to help people live positively with GSD over the past year.

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2022

Plans for future periods (continued)

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 . 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
and signed on their behalf by:



19 December 2022

Nicholas Jones
Trustee

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

**INDEPENDENT EXAMINER'S REPORT
FOR THE YEAR ENDED 31 MARCH 2022**

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 2022.

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:

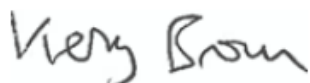
1. accounting records were not kept in respect of the company as required by section 386 of the 2006 Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts 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:

20 December 2022

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 2022**

	Note	Restricted funds 2022 £	Unrestricted funds 2022 £	Total funds 2022 £	<i>Total funds 2021 £</i>
Income from:					
Donations and legacies	4	38,889	68,391	107,280	105,582
Other trading activities	5	1,251	16,204	17,455	14,740
Investments	6	-	14	14	42
Other income	7	7,000	-	7,000	2,517
Total income		47,140	84,609	131,749	122,881
Expenditure on:					
Raising funds	8	-	-	-	1,972
Charitable activities		56,635	88,213	144,848	139,696
Total expenditure		56,635	88,213	144,848	141,668
Net expenditure		(9,495)	(3,604)	(13,099)	(18,787)
Transfers between funds	18	235	(235)	-	-
Net movement in funds		(9,260)	(3,839)	(13,099)	(18,787)
Reconciliation of funds:					
Total funds brought forward		82,196	27,301	109,497	128,284
Total funds carried forward		72,936	23,462	96,398	109,497

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

The notes on pages 12 to 32 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 2022

	Note	2022 £	2021 £
Fixed assets			
Intangible assets	14	4,789	9,577
Tangible assets	15	1,133	1,511
		<u>5,922</u>	<u>11,088</u>
Current assets			
Debtors	16	5,771	11,915
Cash at bank and in hand		89,950	95,243
		<u>95,721</u>	<u>107,158</u>
Creditors: amounts falling due within one year	17	(5,245)	(8,749)
Total net assets		<u><u>96,398</u></u>	<u><u>109,497</u></u>
Charity funds			
Restricted funds	18	72,936	82,196
Unrestricted funds	18	23,462	27,301
Total funds		<u><u>96,398</u></u>	<u><u>109,497</u></u>

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 and signed on their behalf by:

 19 December 2022

Nicholas Jones
Trustee

The notes on pages 12 to 32 form part of these financial statements.

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2022**

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.

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**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2022**

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 revaluation model, intangible assets shall be carried at a revalued amount, being their fair value at the date of revaluation less any subsequent accumulated amortisation and subsequent impairment losses - provided that the fair value can be determined by reference to an active market.

Revaluations are made with sufficient regularity to ensure that the carrying amount does not differ materially from that which would be determined using fair value at the end of the reporting period.

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.

Amortisation is provided on the following basis:

Website development	- 20 % straight line
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**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2022**

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
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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.

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2022

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 accounting estimates and assumptions:

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

In accordance with the Charities SORP FRS 102, the charity has valued the benefit it receives from donated services as £57,225 (2021: £53,416). This is based on the open market value of benefits received.

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**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2022**

4. Income from donations and legacies

	Restricted funds 2022 £	Unrestricted funds 2022 £	Total funds 2022 £	<i>Total funds 2021 £</i>
Donations	385	5,369	5,754	8,751
Grants	35,964	4,950	40,914	40,808
Donations in kind	2,540	54,685	57,225	53,416
Gift aid	-	3,387	3,387	2,607
Total 2022	38,889	68,391	107,280	105,582
<i>Total 2021</i>	<i>25,794</i>	<i>79,788</i>	<i>105,582</i>	

5. Income from other trading activities

Income from fundraising events

	Restricted funds 2022 £	Unrestricted funds 2022 £	Total funds 2022 £	<i>Total funds 2021 £</i>
Fundraising events	1,185	15,253	16,438	13,455
<i>Total 2021</i>	<i>1,716</i>	<i>11,739</i>	<i>13,455</i>	

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2022**

5. Income from other trading activities (continued)

Income from non charitable trading activities

	Restricted funds 2022 £	Unrestricted funds 2022 £	Total funds 2022 £	<i>Total funds 2021 £</i>
Subscriptions	-	945	945	1,174
Book Sales	66	6	72	111
Total 2022	<u>66</u>	<u>951</u>	<u>1,017</u>	<u>1,285</u>
<i>Total 2021</i>	<u>68</u>	<u>1,217</u>	<u>1,285</u>	

6. Investment income

	Unrestricted funds 2022 £	Total funds 2022 £	<i>Total funds 2021 £</i>
Investment income	<u>14</u>	<u>14</u>	<u>42</u>
<i>Total 2021</i>	<u>42</u>	<u>42</u>	

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**NOTES TO THE FINANCIAL STATEMENTS
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7. Other incoming resources

	Restricted funds 2022 £	Unrestricted funds 2022 £	Total funds 2022 £	<i>Total funds 2021 £</i>
Other income	7,000	-	7,000	2,517
<i>Total 2021</i>	<i>1,053</i>	<i>1,464</i>	<i>2,517</i>	

8. Expenditure on raising funds

Costs of raising voluntary income

	Restricted funds 2022 £	Total funds 2022 £	<i>Total funds 2021 £</i>
Fundraising Expenses	-	-	1,972
<i>Total 2021</i>	<i>1,972</i>	<i>1,972</i>	

9. Analysis of grants

	Grants 2022 £	Total funds 2022 £	<i>Total funds 2021 £</i>
Grants	1,090	1,090	2,520
<i>Total 2021</i>	<i>2,520</i>	<i>2,520</i>	

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9. Analysis of grants (continued)

In 2022 no grants were given to institutions (2021: 0) and 5 to individuals (2021: 15).

10. Analysis of expenditure by activities

	Activities undertaken directly 2022 £	Grant funding of activities 2022 £	Support costs 2022 £	Total funds 2022 £	<i>Total funds 2021 £</i>
Charitable activities	96,930	1,090	46,828	144,848	139,696
	<hr/>	<hr/>	<hr/>	<hr/>	<hr/>
<i>Total 2021</i>	<hr/> <i>94,030</i> <hr/>	<hr/> <i>2,520</i> <hr/>	<hr/> <i>43,146</i> <hr/>	<hr/> <i>139,696</i> <hr/>	

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10. Analysis of expenditure by activities (continued)

Analysis of direct costs

	Total funds 2022 £	<i>Total funds 2021 £</i>
Conference	-	5,914
Walking course	-	-
Consultancy	56,725	51,916
Travel and accommodation expenses	277	-
Staff costs	14,273	36,200
Freelancer consulting costs	25,655	-
	<hr/> 96,930 <hr/>	<hr/> 94,030 <hr/>

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**NOTES TO THE FINANCIAL STATEMENTS
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10. Analysis of expenditure by activities (continued)

Analysis of support costs

	Total funds 2022 £	<i>Total funds 2021 £</i>
Rent	312	312
Office costs	3,316	2,622
Online services	493	396
Website and computer costs	9,827	10,176
Sundry expenses	65	2,418
Subscriptions	174	352
Insurance	793	815
Printing, post and stationery	4,173	5,595
Fundraising	369	278
Currency gains/losses	-	246
Depreciation - office equipment	378	669
Amortisation - website development	4,787	4,787
Accountancy & payroll	7,193	11,264
Consultancy	6,500	-
Independent examiners fee	2,593	2,419
Staff costs	5,855	797
Total 2022	46,828	43,146

During the year ended 31 March 2022, the company incurred the following Governance costs:

£9,786 (2021 - £13,683) included within the table above.

11. Independent examiner's remuneration

The independent examiner's remuneration amounts to an independent examiner fee of £2,593 (2021 - £2,419).

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12. Staff costs

	2022	<i>2021</i>
	£	£
Wages and salaries	19,777	<i>36,200</i>
Pension costs	351	<i>797</i>
	20,128	<i>36,997</i>

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

	2022	<i>2021</i>
	No.	No.
	1	<i>1</i>

The key management personnel of the charity are the Trustees and Chief Executive. Total employee benefits of key management personnel of the charity were £14,801 (*2021: £NIL*).

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 (*2021 - £NIL*).

During the year ended 31 March 2022, expenses totalling £562 were reimbursed or paid directly to 1 Trustee (*2021 - £NIL to 0 Trustees*) to cover expenses incurred relating to postage and the ICIEM 2021 conference.

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14. Intangible assets

	Website development £
Cost	
At 1 April 2021	23,938
At 31 March 2022	<u>23,938</u>
Amortisation	
At 1 April 2021	14,361
Charge for the year	4,788
At 31 March 2022	<u>19,149</u>
Net book value	
At 31 March 2022	<u><u>4,789</u></u>
<i>At 31 March 2021</i>	<u><u>9,577</u></u>

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15. Tangible fixed assets

	Office equipment £
Cost or valuation	
At 1 April 2021	7,369
At 31 March 2022	<u>7,369</u>
Depreciation	
At 1 April 2021	5,858
Charge for the year	378
At 31 March 2022	<u>6,236</u>
Net book value	
At 31 March 2022	<u><u>1,133</u></u>
<i>At 31 March 2021</i>	<u><u>1,511</u></u>

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16. Debtors

	2022	<i>2021</i>
	£	<i>£</i>
Due within one year		
Trade debtors	5,002	<i>9,275</i>
Other debtors	50	<i>50</i>
Prepayments and accrued income	719	<i>2,590</i>
	5,771	<i>11,915</i>

17. Creditors: Amounts falling due within one year

	2022	<i>2021</i>
	£	<i>£</i>
Trade creditors	-	<i>2,406</i>
Other creditors	1,266	<i>1,622</i>
Accruals and deferred income	3,979	<i>4,721</i>
	5,245	<i>8,749</i>

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**NOTES TO THE FINANCIAL STATEMENTS
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18. Statement of funds

Statement of funds - current year

	Balance at 1 April 2021 £	Income £	Expenditure £	Transfers in/out £	Balance at 31 March 2022 £
Unrestricted funds					
General Funds - all funds	27,301	84,609	(88,213)	(235)	23,462
Restricted funds					
Type 2 Pompe	13,740	95	(1,959)	-	11,876
Type 5 Mcardle	12,185	1,693	(3,020)	-	10,858
Type 3 Cori	3,478	442	-	-	3,920
Type 1 Van Gierke	12,381	6,006	-	-	18,387
Type 6 Hers Fund	602	-	-	-	602
Hardship Fund	15	-	(250)	235	-
Conferences	10,958	22,440	(10,093)	-	23,305
Medical Advisory Board	2,065	-	-	-	2,065
Specialist Care Advisor	3,590	15,064	(17,587)	-	1,067
Type 0	165	-	-	-	165
Patient Education and Empowerment	23,017	1,400	(23,726)	-	691
	82,196	47,140	(56,635)	235	72,936
Total of funds	109,497	131,749	(144,848)	-	96,398

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18. Statement of funds (continued)

Statement of funds - prior year

	<i>Balance at 1 April 2020 £</i>	<i>Income £</i>	<i>Expenditure £</i>	<i>Balance at 31 March 2021 £</i>
Unrestricted funds				
General Funds - all funds	16,548	94,250	(83,497)	27,301
Restricted funds				
Type 2 Pompe	14,655	1,905	(2,820)	13,740
Type 5 Mcardle	11,846	1,749	(1,410)	12,185
Type 3 Cori	3,528	-	(50)	3,478
Type 1 Van Gierke	12,381	-	-	12,381
Type 6 Hers Fund	602	-	-	602
Hardship Fund	115	-	(100)	15
Conferences	12,742	5,706	(7,490)	10,958
Medical Advisory Board	2,065	-	-	2,065
Specialist Care Advisor	25,445	10,701	(32,556)	3,590
Type 0	165	-	-	165
Patient Education and Empowerment	28,192	8,570	(13,745)	23,017
	111,736	28,631	(58,171)	82,196
Total of funds	128,284	122,881	(141,668)	109,497

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**NOTES TO THE FINANCIAL STATEMENTS
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19. Summary of funds

Summary of funds - current year

	Balance at 1 April 2021 £	Income £	Expenditure £	Transfers in/out £	Balance at 31 March 2022 £
General funds	27,301	84,609	(88,213)	(235)	23,462
Restricted funds	82,196	47,140	(56,635)	235	72,936
	<u>109,497</u>	<u>131,749</u>	<u>(144,848)</u>	<u>-</u>	<u>96,398</u>

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**NOTES TO THE FINANCIAL STATEMENTS
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19. Summary of funds (continued)

Summary of funds - prior year

	<i>Balance at 1 April 2020 £</i>	<i>Income £</i>	<i>Expenditure £</i>	<i>Balance at 31 March 2021 £</i>
General funds	16,548	94,250	(83,497)	27,301
Restricted funds	111,736	28,631	(58,171)	82,196
	<u>128,284</u>	<u>122,881</u>	<u>(141,668)</u>	<u>109,497</u>

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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.

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.

Patient Education and Empowerment

Supporting patients and families by providing family days.

Transfers between funds

A transfer of £235 was made during the year from the general fund to the hardship fund to cover the deficit at the year end.

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**NOTES TO THE FINANCIAL STATEMENTS
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20. Analysis of net assets between funds

Analysis of net assets between funds - current year

	Restricted funds 2022 £	Unrestricted funds 2022 £	Total funds 2022 £
Tangible fixed assets	-	1,133	1,133
Intangible fixed assets	-	4,789	4,789
Current assets	73,643	22,078	95,721
Creditors due within one year	(707)	(4,538)	(5,245)
Total	72,936	23,462	96,398

Analysis of net assets between funds - prior year

	<i>Restricted funds 2021 £</i>	<i>Unrestricted funds 2021 £</i>	<i>Total funds 2021 £</i>
Tangible fixed assets	-	1,511	1,511
Intangible fixed assets	-	9,577	9,577
Current assets	83,155	24,003	107,158
Creditors due within one year	(959)	(7,790)	(8,749)
Total	82,196	27,301	109,497

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NOTES TO THE FINANCIAL STATEMENTS
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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 12 represents the contributions payable by the Charity to these funds.

22. Related party transactions

There were no related party transactions in the year ended 31 March 2022.