

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

UNAUDITED

TRUSTEES' REPORT AND FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2024

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 2024**

Trustees

Nicholas Jones
Ailsa Arthur
Sarah Chikhani
Rachel Thomas
Dr Florence Osborne, Chair
Dr Charlotte Dawson
Kempton Rees

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 2024

The Trustees present their annual report together with the financial statements of the company for the year 1 April 2023 to 31 March 2024. 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 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. Please see Review of activities section for details of our current strategy.

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.

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TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2024

Objectives and activities (continued)

d. Grant-making policies

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

Achievements and performance

a. Review of activities

During the 2023-24 financial year, we continued work to deliver our current strategic goals. These are framed around the priorities identified by people affected by GSDs through community research and a listening exercise. They comprise:

Theme: Support across the community.

Goal: Everyone affected will be connected to an active and supportive GSD community.

Theme: Help with living well.

Goal: People with any GSD will be offered the information and activities they need to live well with the condition.

Theme: Better treatments and service access.

Goal: The community will experience improved management, treatment and service access.

Theme: Strong and effective organisation.

Goal: AGSD-UK will grow sustainably, with robust governance, to increase our impact.

Our progress against these goals is outlined below.

Support across the community

In May 2023 for the first time since the Covid pandemic we were able to hold an in-person weekend event for community members.

The event attracted over 100 people affected by a range of GSDs over the course of the weekend.

The programme was developed in partnership with people affected and in line with our three goals it was designed to include opportunities for:

- meeting and sharing experiences with other people affected
- discussing key topics relating to life with the condition and trying out new therapeutic activities
- hearing from leading experts about latest research and developments in treatment and management of the different GSDs

The evaluation forms completed showed that:

- 98% said the event enabled them to connect with others with similar experiences
- 98% said the event gave them the chance to gain tips about living with GSDs
- 96% said the event allowed them to become better informed about research and developments in the field of GSDs

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TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2024

Achievements and performance (continued)

- 95% said the event provided the opportunity to get information about support and services that are available
- 100% said they had fun and enjoyed themselves

We have been overwhelmed by the volume of positive feedback received, of which the following are just a small selection of typical examples:

- "Spot on excellent. Love to come again."
- "Learned more about my disease today than I ever have before."
- "Great organisation. Informative programme and social opportunity to connect with others."
- "Fabulous weekend! ...Loved the whole conference. Great speakers and workshops."
- "It was a very positive weekend. Informative and fun."
- "Our first one, loved every minute. Thank you! We'll be back next year. I've learned more today than when my son was diagnosed."

Over the course of the financial year our care advisor and benefits service provided support to more than 150 individuals and families. This involved liaison with multiple agencies, including social services, education, health, children's services, family support charities, housing and employers.

The range of emotional and practical support provided included help for community members to secure:

- Home adaptations and living aids
- Additional support through education, health and care plans
- Reasonable adjustments at work
- Access to a full range of benefit entitlements plus financial support grants
- Enhanced social care packages

The feedback received reflected the difference the service had made for people affected, as shown by these examples:

- "Having the support and resources provided by AGSD charity is not only incredibly valuable but also uplifting...The impact they make on people's lives is truly remarkable, and I am grateful to have them by my side."
- "It is rare to find understanding and empathy like yours and it has been invaluable discussing the challenges we face as a family with someone who has knowledge of this rare condition."
- "You have made me feel that I'm not a nuisance and that my feelings did matter at work."
- "I have Pompe disease, which has confined me mostly to the upstairs of my home...Given my mobility issues, frequent trips up and down were impossible... [AGSD-UK's] efforts resulted in securing funding for a downstairs room and bathroom...I had no idea that such assistance was possible, and I cannot overstate how much having a downstairs room will positively impact my life."
- "Your organisation's commitment to diversity and cultural sensitivity is greatly appreciated, and it is evident that you are making a real difference in the lives of those you assist."

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TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2024

Achievements and performance (continued)

Help with living well

During 2023-24 we began a series of online Living well socials offering the opportunity to try out different therapeutic activities such as guided visualisation and affirmations.

The sessions have had a loyal following with people staying in touch and supporting each other in between and have attracted very positive feedback:

- "I am absolutely thrilled and immensely grateful for the positive mindset social meeting. It was truly a wonderful experience. Managing life while dealing with a child who has no cure can be incredibly challenging, and having this support system is like a breath of fresh air. I felt rejuvenated and uplifted after attending."
- "We were led into positive thinking and positive affirmations, and the time went too quickly. An hour later, we'd made new friends, re-acquainted ourselves with others, and we know there's always someone there for us, and that we are well supported."
- "The energy everyone brought was fantastic, and the discussion topic was particularly engaging. I'm eagerly anticipating our next session."

Meanwhile three McArdle's walking courses, one for adults; one for children and parents; plus a future leaders' course, collectively attracted 42 people –the largest number ever. Feedback, as always, was extremely positive and huge thanks go Andrew Wakelin for his leadership and to all the volunteers who made the courses such a success.

- "The care, planning and support all week were exemplary!"
- "This week [we] had a glimpse that McArdle's can give our children more than it takes. This was profound for us."

We continued to publish regular editions of our Glisten magazine, reaching over 1,500 community members with its wide ranging content including latest developments, management tips and experiences of life with the condition. There were 37,460 visits to our website, which provides information and signposting about different GSD variants and we also developed new information sheets that were very well received:

- "These are super! Very helpful and full of good advice/ ideas."

Better treatments and service access

During this period we took every opportunity to support GSD community members to participate in research, helping health professionals and market researchers with study design, securing community involvement in developing patient information for therapy trials, promoting participation in discussion to support ethics committee applications and helping to shape and recruit to a number of surveys relating to different GSDs. We were delighted that the generous support of the Mosawi Foundation enabled us to fund two PhD programmes at Loughborough University. These relate to diet, exercise and mental health in hepatic GSDs, which had been identified as priorities for further investigation and information provision.

We successfully contributed evidence to NICE, the Scottish Medicines Consortium and the All Wales Medicines Strategy Group supporting access to new enzyme replacement therapies for Pompe, resulting in much needed treatment options for people affected. We fielded an expert McArdle's team at a meeting to foster collaborations with drug development companies to prompt the development of treatments for unmet needs, and generated a number of leads to follow up. We took part in an international online focus group bringing the APBD and GSD IV communities together to identify priority areas for collaboration and work towards making therapies a reality. We also attended and facilitated professionals' meetings, continuing our work in partnership with other organisations to drive improvements in care.

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TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2024

Achievements and performance (continued)

Strong and effective organisation

We continued our work to benchmark the organisation against established voluntary sector standards, strengthening our processes and policies to ensure these are robust and in line with best practice. This included developing a clear statement of our values and reviewing the way we recognise the dedicated volunteers who are so vital to our work and to whom we give our heartfelt thanks.

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 17). The general reserves are used to support the on going activities of the Association. The unrestricted general reserve now stands at £43,859 which is an increase from the previous year (£24,159). The trustees' future focus will be on increasing income while tightly managing costs. The total restricted funds is now £84,223 (2023: £59,194).

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 funds freely available for use by the charity at the year end at the discretion of the Trustees, amount to the unrestricted reserves less the unrestricted tangible fixed assets of £798. Our free reserves at 31 March 2024 are therefore £43,061 (2023: £23,145).

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".

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2024

Structure, governance and management (continued)

b. Methods of appointment or election of Trustees

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

c. Organisational structure and decision-making policies

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

The Board of Trustees delivers the strategy through the 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 2024

Structure, governance and management (continued)

Plans for future periods

For the period April 2024-March 25 our focus remains on delivery of our plan in support of our strategy goals. We aim to increase the range of on and off line support and activities we offer, including staging a further highly-valued, full-scale community event, to connect people affected with others experiencing this rare and isolating condition and equip them with approaches that help with living well. We will also take forward funding of two PhD studentships focused on eating, exercise, mental health and digital biomarkers in hepatic GSDs which aim to generate evidence-based pathways and resources for better management of the condition for people affected and professionals.

In order to support these activities we continue our development of community fundraising and applications to grant making trusts, as well as our engagement with organisations in the field. We are hugely grateful to all those individuals who have helped raise funds for our vital services and to the trusts and treatment industry partners including Amicus, Astellas, Beam, the Mosawi Foundation, Sanofi, Spark, Ultragenyx and Vitaflo, whose charitable donations make our work possible.

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).

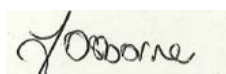
Company law requires the Trustees to prepare financial statements for each financial . Under company law, the Trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the company and of its incoming resources and application 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 21 January 2025

and signed on their behalf by:



Dr Florence Osborne
Chair

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

**INDEPENDENT EXAMINER'S REPORT
FOR THE YEAR ENDED 31 MARCH 2024**

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 2024.

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: *Helen Blundell*

Helen Blundell

Dated: 23 January 2025

LLB FCA FCIE DChA

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 2024**

	Note	Restricted funds 2024 £	Unrestricted funds 2024 £	Total funds 2024 £	Total funds 2023 £
Income from:					
Donations and legacies	4	155,150	62,245	217,395	126,955
Other trading activities	5	6,248	16,365	22,613	15,985
Investments	6	-	1,120	1,120	451
Other income	7	-	1,149	1,149	325
Total income		161,398	80,879	242,277	143,716
Expenditure on:					
Charitable activities		136,479	61,069	197,548	156,761
Total expenditure		136,479	61,069	197,548	156,761
Net income/(expenditure)		24,919	19,810	44,729	(13,045)
Transfers between funds	17	373	(373)	-	-
Net movement in funds		25,292	19,437	44,729	(13,045)
Reconciliation of funds:					
Total funds brought forward		59,194	24,159	83,353	96,398
Total funds carried forward		84,486	43,596	128,082	83,353

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

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

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

BALANCE SHEET
AS AT 31 MARCH 2024

	Note	2024 £	2023 £
Fixed assets			
Tangible assets	14	798	1,014
		<u>798</u>	<u>1,014</u>
Current assets			
Debtors	15	3,478	6,865
Cash at bank and in hand		130,666	81,619
		<u>134,144</u>	<u>88,484</u>
Creditors: amounts falling due within one year		(6,860)	(6,145)
	16	<u></u>	<u></u>
Total net assets		<u><u>128,082</u></u>	<u><u>83,353</u></u>
Charity funds			
Restricted funds	17	84,486	59,194
Unrestricted funds	17	43,596	24,159
		<u></u>	<u></u>
Total funds		<u><u>128,082</u></u>	<u><u>83,353</u></u>

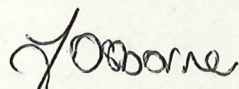
The company was entitled to exemption from audit under section 477 of the Companies Act 2006.

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 21 January 2025 and signed on their behalf by:



Dr Florence Osborne
Chair

The notes on pages 12 to 30 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 2024

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 2019), 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 is a private company limited by guarantee and 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.

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2024

2. Accounting policies (continued)

2.4 Expenditure (continued)

Expenditure on charitable activities is incurred on directly undertaking the activities which further the company's objectives, as well as any associated support costs.

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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ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2024**

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 3% 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.

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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 donations in kind of £52,271 (2023: £59,396). This is based on the open market value of benefits received.

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4. Income from donations and legacies

	Restricted funds 2024 £	Unrestricted funds 2024 £	Total funds 2024 £	<i>Total funds 2023 £</i>
Donations	10,000	11,556	21,556	6,797
Legacies	-	5,000	5,000	-
Grants	122,850	11,700	134,550	59,500
Donations in kind	22,300	29,971	52,271	59,396
Gift aid	-	4,018	4,018	1,262
Total 2024	155,150	62,245	217,395	126,955
<i>Total 2023</i>	<i>63,879</i>	<i>63,076</i>	<i>126,955</i>	

5. Income from other trading activities

Income from fundraising events

	Restricted funds 2024 £	Unrestricted funds 2024 £	Total funds 2024 £	<i>Total funds 2023 £</i>
Fundraising events	6,248	15,490	21,738	15,145
<i>Total 2023</i>	<i>4,594</i>	<i>10,551</i>	<i>15,145</i>	

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5. Income from other trading activities (continued)

Income from non charitable trading activities

	Restricted funds 2024 £	Unrestricted funds 2024 £	Total funds 2024 £	<i>Total funds 2023 £</i>
Subscriptions	-	875	875	800
Book Sales	-	-	-	40
Total 2024	<u>-</u>	<u>875</u>	<u>875</u>	<u>840</u>
<i>Total 2023</i>	<u>20</u>	<u>820</u>	<u>840</u>	

6. Investment income

	Unrestricted funds 2024 £	Total funds 2024 £	<i>Total funds 2023 £</i>
Investment income	<u>1,120</u>	<u>1,120</u>	<u>451</u>
<i>Total 2023</i>	<u>451</u>	<u>451</u>	

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7. Other incoming resources

	Unrestricted funds 2024 £	Total funds 2024 £	<i>Total funds 2023 £</i>
Other income	1,149	1,149	325
<i>Total 2023</i>	325	325	

8. Analysis of grants

	Grants 2024 £	Grants to Institution 2024 £	Total funds 2024 £	<i>Total funds 2023 £</i>
Grants	420	12,308	12,728	273
<i>Total 2023</i>	273	-	273	

In 2024 1 grant was given to institutions (2023: 0) and 1 to individuals (2023: 2).

9. Analysis of expenditure by activities

	Activities undertaken directly 2024 £	Grant funding of activities 2024 £	Support costs 2024 £	Total funds 2024 £	<i>Total funds 2023 £</i>
Charitable activities	152,079	12,728	32,741	197,548	156,761
<i>Total 2023</i>	123,205	273	33,283	156,761	

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9. Analysis of expenditure by activities (continued)

Analysis of direct costs

	Charitable activities 2024 £	Total funds 2024 £	<i>Total funds 2023 £</i>
Staff costs	24,533	24,533	22,408
Conference expenses	27,449	27,449	-
Walking Course	9,848	9,848	6,709
Consultancy	52,271	52,271	59,396
Travel and accommodation expenses	928	928	3,095
Freelancer consulting costs	37,050	37,050	29,434
Patient and Family meetings	-	-	2,163
Total 2024	<u>152,079</u>	<u>152,079</u>	<u>123,205</u>
<i>Total 2023</i>	<u>123,205</u>	<u>123,205</u>	

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9. Analysis of expenditure by activities (continued)

Analysis of support costs

	Charitable activities 2024 £	Total funds 2024 £	<i>Total funds 2023 £</i>
Rent	1,842	1,842	312
Office Costs	308	308	396
Online services	962	962	968
Website and computer costs	10,594	10,594	8,628
Sundry expenses	425	425	-
Subscriptions	599	599	138
Insurance	706	706	717
Printing, post and stationery	3,189	3,189	1,578
Fundraising	101	101	(43)
Depreciation - office equipment	216	216	288
Amortisation - website development	-	-	4,789
Staff training	-	-	787
Accountancy & payroll	9,602	9,602	9,827
Independent examiners fee	2,963	2,963	2,773
Staff costs	1,234	1,234	2,125
Total 2024	<u>32,741</u>	<u>32,741</u>	<u>33,283</u>
<i>Total 2023</i>	<u>33,283</u>	<u>33,283</u>	

During the year ended 31 March 2024, the company incurred the following Governance costs:

£12,590 (2023 - £12,600) included in the table above.

10. Independent examiner's remuneration

The independent examiner's remuneration amounts to an independent examiner fee of £2,963 (2023 - £2,773).

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11. Staff costs

	2024	2023
	£	£
Wages and salaries	24,000	24,000
Social security costs	1,234	-
Pension costs	533	533
	25,767	24,533

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

2024	2023
No.	No.
1	1

The key management personnel of the charity are the Trustees and Chief Executive. Total employee benefits of key management personnel of the charity were £24,533 (2023: £24,533).

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

12. Trustees' remuneration and expenses

During the year, no Trustees received any remuneration or other benefits (2023 - £NIL).

During the year ended 31 March 2024, expenses totalling £NIL were reimbursed or paid directly to Trustee (2023 - £938 to 1 Trustees) to cover expenses incurred relating to postage and a walking course.

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13. Intangible assets

	Website development £
Cost	
At 1 April 2023	23,938
At 31 March 2024	23,938
Amortisation	
At 1 April 2023	23,938
At 31 March 2024	23,938
Net book value	
At 31 March 2024	-
<i>At 31 March 2023</i>	-

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14. Tangible fixed assets

	Office equipment £
Cost or valuation	
At 1 April 2023	7,538
At 31 March 2024	<u>7,538</u>
Depreciation	
At 1 April 2023	6,524
Charge for the year	216
At 31 March 2024	<u>6,740</u>
Net book value	
At 31 March 2024	<u><u>798</u></u>
At 31 March 2023	<u><u>1,014</u></u>

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15. Debtors

	2024	2023
	£	£
Due within one year		
Trade debtors	-	5,674
Other debtors	2,512	50
Prepayments and accrued income	966	1,141
	<u>3,478</u>	<u>6,865</u>

16. Creditors: Amounts falling due within one year

	2024	2023
	£	£
Other creditors	1,933	2,474
Accruals and deferred income	4,927	3,671
	<u>6,860</u>	<u>6,145</u>

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17. Statement of funds

Statement of funds - current year

	Balance at 1 April 2023 £	Income £	Expenditure £	Transfers in/out £	Balance at 31 March 2024 £
Unrestricted funds					
General Funds - all funds	24,159	80,879	(61,069)	(373)	43,596
Restricted funds					
Type 2 Pompe	7,294	-	(3,353)	-	3,941
Type 5 Mcardle	8,528	28,658	(32,331)	-	4,855
Type 3 Cori	3,309	-	(2,934)	-	375
Type 1 Van Gierke	17,532	-	(4,757)	-	12,775
Type 6 Hers Fund	602	-	-	-	602
Conferences	21,331	1,190	(22,631)	110	-
Type 0	165	-	-	-	165
Better treatments and service access	-	15,733	(15,996)	263	-
Help with living well	-	23,833	(23,826)	-	7
Support across the community	433	18,134	(18,343)	-	224
PHD Project	-	73,850	(12,308)	-	61,542
	59,194	161,398	(136,479)	373	84,486
Total of funds	83,353	242,277	(197,548)	-	128,082

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17. Statement of funds (continued)

Statement of funds - prior year

	<i>Balance at 1 April 2022 £</i>	<i>Income £</i>	<i>Expenditure £</i>	<i>Transfers in/out £</i>	<i>Balance at 31 March 2023 £</i>
Unrestricted funds					
General Funds - all funds	23,462	75,223	(73,087)	(1,439)	24,159
Restricted funds					
Type 2 Pompe	11,876	-	(4,582)	-	7,294
Type 5 Mcardle	10,858	15,376	(17,706)	-	8,528
Type 3 Cori	3,920	-	(611)	-	3,309
Type 1 Van Gierke	18,387	-	(855)	-	17,532
Type 6 Hers Fund	602	-	-	-	602
Conferences	23,305	2,500	(4,474)	-	21,331
Medical Advisory Board	2,065	-	(2,065)	-	-
Specialist Care Advisor	1,067	-	(1,067)	-	-
Type 0	165	-	-	-	165
Patient Education and Empowerment	691	4,617	(5,308)	-	-
Better treatments and service access	-	13,833	(13,833)	-	-
Help with living well	-	16,833	(18,272)	1,439	-
Support across the community	-	15,334	(14,901)	-	433
	72,936	68,493	(83,674)	1,439	59,194
Total of funds	96,398	143,716	(156,761)	-	83,353

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18. Summary of funds

Summary of funds - current year

	Balance at 1 April 2023 £	Income £	Expenditure £	Transfers in/out £	Balance at 31 March 2024 £
General funds	24,159	80,879	(61,069)	(373)	43,596
Restricted funds	59,194	161,398	(136,479)	373	84,486
	<u>83,353</u>	<u>242,277</u>	<u>(197,548)</u>	<u>-</u>	<u>128,082</u>

Summary of funds - prior year

	<i>Balance at 1 April 2022 £</i>	<i>Income £</i>	<i>Expenditure £</i>	<i>Transfers in/out £</i>	<i>Balance at 31 March 2023 £</i>
General funds	23,462	75,223	(73,087)	(1,439)	24,159
Restricted funds	72,936	68,493	(83,674)	1,439	59,194
	<u>96,398</u>	<u>143,716</u>	<u>(156,761)</u>	<u>-</u>	<u>83,353</u>

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18. 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.

Better treatments and service access

Supporting activities to promote better treatments and service access through research engagement and work with professionals and partners.

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18. Summary of funds (continued)

Help with living well

Supporting activities to enable people affected to live well with GSDs, including information, educational programmes and therapeutic activities.

Support across the community

Supporting activities to ensure support is available across the GSD community.

PHD Projects

Grant contribution to PhD studentship 1
Eating, physical activity and mental health.

Grant contribution to PhD studentship 2
Investigating digital biomarkers to support safe physical activity.

Transfers between funds

A transfer of £263 was made during the year from the general fund to the Better treatments and service access fund and of £110 to the Conferences fund to cover the deficit at the year end.

19. Analysis of net assets between funds

Analysis of net assets between funds - current period

	Restricted funds 2024 £	Unrestricted funds 2024 £	Total funds 2024 £
Tangible fixed assets	-	798	798
Current assets	86,029	48,115	134,144
Creditors due within one year	(1,543)	(5,317)	(6,860)
Total	84,486	43,596	128,082

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19. Analysis of net assets between funds (continued)

Analysis of net assets between funds - prior period

	<i>Restricted funds 2023 £</i>	<i>Unrestricted funds 2023 £</i>	<i>Total funds 2023 £</i>
Tangible fixed assets	-	1,014	1,014
Current assets	60,955	27,529	88,484
Creditors due within one year	(1,761)	(4,384)	(6,145)
Total	59,194	24,159	83,353

20. 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 11 represents the contributions payable by the Charity to these funds. Included in other creditors is a balance of £104 (2023 - £107) which relates to the pension fund.

21. Related party transactions

There were no related party transactions in the year ended 31 March 2024.