

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED

England & Wales · Charity number 1132271

Details

Other names AGSD (UK), POMPE UK

Status Registered

Legal form Charitable company

Company number [06981121](#)

Registered 2009-10-22

Register [View on the Charity Commission register](#)

Contact

Address A G S D UK
PO Box 699
Southampton
SO50 0QT

Phone 0300 123 2790

Email info@agsd.org.uk

Website www.agsd.org.uk

Activities

Objects: THE RELIEF OF SICKNESS, PARTICULARLY OF PERSONS SUFFERING FROM ANY FORM OF GLYCOGENSTORAGE DISEASE

Activities: We are the national charity for people experiencing Glycogen Storage Disease, their families and carers as well as for medical professionals working in this field. As the UK's main charity in this area, we support people with the disease, promote research and raise public awareness of GSDs.

Classification

- **How:** Makes Grants To Individuals, Makes Grants To Organisations, Provides Human Resources, Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research, Acts As An Umbrella Or Resource Body
- **What:** Education/training, The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** Children/young People, People With Disabilities, Other Defined Groups

Geography

- **Area of benefit:** UNDEINED. IN PRACTICE, NATIONAL
- Northern Ireland
- Scotland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£173,952	£212,211	-	-
2024-03-31	£242,277	£197,548	-	-
2023-03-31	£143,716	£156,761	-	-
2022-03-31	£131,749	£144,848	-	-
2021-03-31	£122,881	£141,668	-	-

Trustees

Name	Role	Appointed
Dr Florence Osbourne	Chair	2021-05-01
Ailsa Arthur		2017-10-29
Dr Charlotte Dawson		2023-01-15
Dr Karolina Stepien		2026-01-18
Kempton Rees		2023-01-15
Rachel Thomas		2020-07-15
Sarah Chikhani		2020-07-12

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED

England & Wales - Charity number 1132271

Accounts

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

UNAUDITED

TRUSTEES' REPORT AND FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2025

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 2025**

Trustees

Nicholas Jones (resigned 18 January 2026)
Ailsa Arthur
Sarah Chikhani
Rachel Thomas
Dr Florence Osborne, Chair
Dr Charlotte Dawson
Kempton Rees
Karolina Stepień (appointed 18 January 2026)

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 2025

The Trustees present their annual report together with the financial statements of the company for the year 1 April 2024 to 31 March 2025. 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.

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2025

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 2024-25 financial year we continued to work towards the goals of our current strategic plan. These are drawn from priorities identified by community members and 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.

Support across the community

Over the course of the year the intensive advocacy provided by our care and benefits advisors enabled community members to access much needed services such as home adaptations and equipment grants, education and health care packages, transport, enhanced social care and a range of welfare benefits. Individuals and families also received valued support with issues like dealing with diagnosis, parenting and employment rights. Their feedback included:

- "AGSD UK truly is a breath of fresh air for people facing the challenges of rare conditions. Your charity provides more than just advice; you offer a lifeline of empathy, understanding, and non-judgmental support to those who need it most."
- "I would like to express my heartfelt gratitude to AGSD UK. I have Pompe disease, and at times, it can make you feel isolated. Coping with the constant changes to your health and mobility, as well as the day-to-day challenges, can be incredibly tough. AGSD UK has been an unwavering source of support for me."
- "[AGSD-UK advisors] have been instrumental in guiding me through the complexities of benefit programs, including DLA and carer's allowance, and have also provided invaluable assistance in assessing my overall benefit entitlements. Their support extended beyond paperwork, as they even helped me access food vouchers during times of real hardship."

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TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2025

Achievements and performance (continued)

Our local get-togethers connecting people with others affected also received a very positive response from those attending:

- “We had an amazing time and thoroughly enjoyed ourselves. It was such a valuable experience to meet other families facing similar health challenges, which made us feel much less isolated.”
- Living with such a rare condition can be tough, especially when people don’t always understand what we go through, so connecting with others who do was incredibly comforting.”
- “...it was great to connect with other parents of children with GSD and share our experiences, challenges and daily worries.”

Help with living well

Two McArdle’s walking courses for under 21s and for adults took place in Wales during July and August 2024 and, as usual, were greatly appreciated by those taking part:

- “Just wanted to thank you again for organising the walking course and encouraging me to come on it. I had a great time and feel like I learnt a lot.”
- “These weekends/weeks are life-changing and life-affirming. From the bottom of my heart, thank you all for an amazing week.”
- “The twins got to be with other teens, young people and older McArdleites. They got to climb mountains they (and we) would never have attempted and do physical things that were bold and audacious.”
- “I enjoyed the amazing walks that we went on and the cooking. I really liked the activities we did after the walks, like bracelet making, playing games and paddling in the river!”

Our monthly Living well socials continue to be extremely well received and a thriving WhatsApp group has been developed alongside the meetings to facilitate mutual support:

“Wonderful place to be. Love how positive it is. Thank you... for this safe space”

Our regular Glisten magazine packed with information about living with GSDs was widely distributed and further information sheets produced. Website views for the financial year totalled 38,020.

Our Main Event for the community staged during the 2024-5 financial year again received outstanding feedback. The evaluation forms completed showed that:

- 100% said the event enabled them to connect with others with similar experiences
- 100% said the event gave them the chance to gain tips about living with GSDs
- 100% said the event allowed them to become better informed about research and developments in the field of GSDs

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2025

Achievements and performance (continued)

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

The following is just a small selection of the comments received:

- "It was superb. Team was great-very helpful. Would like to attend again."
- "Good mix of scientific updates, patient support and fun activities."
- "Loved the music therapy on Sunday a.m."
- "The whole AGSD-UK team are wonderful –I thoroughly enjoyed the meeting."
- "We were very impressed with the organisation and the agenda."
- "It was a very valuable experience coming to this event with my family as not only did we meet people who are dealing with the same thing as us but also with professionals who mirror the work they do with our centre."
- "Heartfelt thanks for an incredibly well-organised and impactful conference...The programme itself was so well curated, delivering both depth and relevance that kept us all engaged throughout the weekend..."
- "Your hard work, attention to detail and dedication made the event run smoothly and successfully. The sessions were insightful. We truly appreciated it."
- "Thank you so much for looking after us. Your care and attention meant a lot. We're truly grateful for everything you do to keep us comfortable and supported. Thank you."
- "This was our first time at the conference. Everyone was really helpful and supportive. Thank you so much."
- "Excellent weekend -informative and fun. Thank you."

Better treatments and service access

Throughout the year we continued to support and promote multiple opportunities for people affected by GSDs to shape and take part in research and trials to enable the development of better treatments. We also worked with industry, health professionals and other charity partners to influence service quality.

Work began on the two Loughborough University PhD research programmes relating to diet, exercise and mental health and digital biomarkers in hepatic GSDs that we are joint-funding with the generous support of the Mosawi Foundation.

We took part in two further international online meetings organised by the Adult Polyglucosan Body Disease Research Foundation, focused on bringing the APBD and GSD IV communities together to develop a joint action and communications plan. AGSD-UK was also represented at an Aspire biosciences speed-dating event, this time with a view to exploring potential partnerships for new treatments for hepatic GSDs.

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2025

Achievements and performance (continued)

Strong and effective organisation

We continued 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 reviewing ways to ensure our board remains fully inclusive and open to new members to bring a range of skills, ideas and perspectives to our governance and cause. We remain extremely grateful to all those who contribute their time, energy and expertise to help enable AGSD-UK to respond to the needs of those affected by this challenging condition.

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 £35,987 which is a decrease from the previous year (£43,596). The trustees' future focus will be on increasing income while tightly managing costs. The total restricted funds is now £53,836 (2024: £84,486).

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 £594. Our free reserves at 31 March 2025 are therefore £35,393 (2024: £42,798).

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.

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2025

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.

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.

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2025

Structure, governance and management (continued)

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.

Plans for future periods

The period April 2025-26 is the last of our current strategy and we remain focused on delivering our stated goals. This involves further expansion of our support offer and facilitation of peer support, with a wider range of groups to meet the needs of under-served sections of the community, including children and young people.

We will take forward updating of our website, ensuring this contains the current evidence-based information people need to help them live well and is attractive, engaging and easy to navigate.

Our ongoing research support will ensure studies and developments in treatment and management are shaped by the needs of the community.

We will also complete our work to benchmark the organisation against best practice standards for the sector, as part of our quality improvement cycle.

In addition, we will take forward a community listening exercise to inform the key goals for our next three year strategy.

To deliver our plans we will continue to support fundraising efforts within the community, while seeking the help of grant making trusts aligned with our goals and working closely with our valued industry partners.

We would like to express our appreciation to all those individuals and organisations who contribute to our work and our special thanks go to; Amicus, Beam, Community Fund, D'Oyly Carte Charitable Trust, Mosawi Foundation, Sanofi, Ultragenyx and Vitaflor for their commitment to improving life for people affected by GSD.

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

TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2025

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 29/01/2026
and signed on their behalf by:

Florence Osborne

Florence Osborne (Jan 29, 2026 10:18:40 GMT)

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 2025**

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 2025.

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:



Dated: 29 January 2026

Helen Blundell

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
(A company limited by guarantee)

**STATEMENT OF FINANCIAL ACTIVITIES (INCORPORATING INCOME AND EXPENDITURE ACCOUNT)
FOR THE YEAR ENDED 31 MARCH 2025**

	Note	Restricted funds 2025 £	Unrestricted funds 2025 £	Total funds 2025 £	<i>Total funds 2024 £</i>
Income from:					
Donations and legacies	4	89,850	60,009	149,859	217,395
Charitable activities	5	-	830	830	875
Other trading activities	6	5,986	16,042	22,028	21,738
Investments	7	-	1,235	1,235	1,120
Other income	8	-	-	-	1,149
Total income		95,836	78,116	173,952	242,277
Expenditure on:					
Charitable activities		145,124	67,087	212,211	197,548
Total expenditure		145,124	67,087	212,211	197,548
Net (expenditure)/income		(49,288)	11,029	(38,259)	44,729
Transfers between funds	18	18,638	(18,638)	-	-
Net movement in funds		(30,650)	(7,609)	(38,259)	44,729
Reconciliation of funds:					
Total funds brought forward		84,486	43,596	128,082	83,353
Total funds carried forward		53,836	35,987	89,823	128,082

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

The notes on pages 13 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 2025

	Note	2025 £	2024 £
Fixed assets			
Tangible assets	15	594	798
		<u>594</u>	<u>798</u>
Current assets			
Debtors	16	6,149	3,478
Cash at bank and in hand		93,253	130,666
		<u>99,402</u>	<u>134,144</u>
Current liabilities			
Creditors: amounts falling due within one year		(10,173)	(6,860)
	17	<u></u>	<u></u>
Total net assets		<u><u>89,823</u></u>	<u><u>128,082</u></u>
Charity funds			
Restricted funds	18	53,836	84,486
Unrestricted funds	18	35,987	43,596
		<u></u>	<u></u>
Total funds		<u><u>89,823</u></u>	<u><u>128,082</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 29/01/2026
and signed on their behalf by:

Florence Osborne
Florence Osborne (Jan 29, 2026 10:18:40 GMT)

Dr Florence Osborne
Chair

The notes on pages 13 to 30 form part of these financial statements.

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

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2025

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 2025

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
(A company limited by guarantee)

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2025**

2. Accounting policies (continued)

2.7 Tangible fixed assets and depreciation

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

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

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

Depreciation is provided on the following basis:

Office equipment	- 25% reducing balance
------------------	------------------------

2.8 Financial instruments

Debtors

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

Creditors

Short term trade creditors are measured at transaction price.

Cash

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

There are no complex financial instruments.

2.9 Pensions

The pension costs charges in the financial statements comprise contributions payable by the Charity during the year for a defined contribution personal pension plan for staff. The Charity contributes 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.

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

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2025**

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 £55,505 (2024: £52,271). This is based on the open market value of benefits received.

4. Income from donations and legacies

	Restricted funds 2025 £	Unrestricted funds 2025 £	Total funds 2025 £	<i>Total funds 2024 £</i>
Donations	-	6,478	6,478	21,556
Legacies	-	-	-	5,000
Grants	67,290	18,000	85,290	134,550
Donations in kind	22,560	32,945	55,505	52,271
Gift aid	-	2,586	2,586	4,018
Total 2025	<u>89,850</u>	<u>60,009</u>	<u>149,859</u>	<u>217,395</u>
<i>Total 2024</i>	<u>155,150</u>	<u>62,245</u>	<u>217,395</u>	

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2025**

5. Income from charitable activities

	Unrestricted funds 2025 £	Total funds 2025 £	<i>Total funds 2024 £</i>
Subscriptions	830	830	875
<i>Total 2024</i>	875	875	

6. Income from other trading activities

Income from fundraising events

	Restricted funds 2025 £	Unrestricted funds 2025 £	Total funds 2025 £	<i>Total funds 2024 £</i>
Fundraising events	5,986	16,042	22,028	21,738
<i>Total 2024</i>	6,248	15,490	21,738	

7. Investment income

	Unrestricted funds 2025 £	Total funds 2025 £	<i>Total funds 2024 £</i>
Investment income	1,235	1,235	1,120
<i>Total 2024</i>	1,120	1,120	

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2025**

8. Other incoming resources

	Unrestricted funds 2025 £	Total funds 2025 £	<i>Total funds 2024 £</i>
Other income	-	-	1,149
<i>Total 2024</i>	1,149	1,149	

9. Analysis of grants

	Grants to Individuals 2025 £	Grants to Institution 2025 £	Total funds 2025 £	<i>Total funds 2024 £</i>
Grants	1,900	24,616	26,516	12,728
<i>Total 2024</i>	420	12,308	12,728	

In 2025 1 grant was given to institutions (2024: 1) and 8 to individuals (2024: 1).

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2025**

10. Analysis of expenditure by activities

	Activities undertaken directly 2025 £	Grant funding of activities 2025 £	Support costs 2025 £	Total funds 2025 £	<i>Total funds 2024 £</i>
Charitable activities	151,085	26,516	34,610	212,211	197,548
<i>Total 2024</i>	<u>152,079</u>	<u>12,728</u>	<u>32,741</u>	<u>197,548</u>	

Analysis of direct costs

	Charitable activities 2025 £	Total funds 2025 £	<i>Total funds 2024 £</i>
Staff costs	24,533	24,533	24,533
Conference expenses	32,764	32,764	27,449
Walking Course	-	-	9,848
Consultancy	55,505	55,505	52,271
Travel and accommodation expenses	940	940	928
Freelancer consulting costs	37,090	37,090	37,050
Patient and Family meetings	253	253	-
Total 2025	<u>151,085</u>	<u>151,085</u>	<u>152,079</u>
<i>Total 2024</i>	<u>152,079</u>	<u>152,079</u>	

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2025**

10. Analysis of expenditure by activities (continued)

Analysis of support costs

	Charitable activities 2025 £	Total funds 2025 £	<i>Total funds 2024 £</i>
Rent	1,896	1,896	1,842
Office Costs	651	651	308
Online services	1,095	1,095	962
Website and computer costs	8,446	8,446	10,594
Sundry expenses	10	10	425
Subscriptions	566	566	599
Insurance	677	677	706
Printing, post and stationery	4,064	4,064	3,189
Fundraising	320	320	101
Depreciation - office equipment	204	204	216
Amortisation - website development	-	-	-
Staff training	-	-	-
Accountancy & payroll	11,438	11,438	9,602
Independent examiners fee	3,186	3,186	2,963
Staff costs	2,057	2,057	1,234
Total 2025	<u>34,610</u>	<u>34,610</u>	<u>32,741</u>
<i>Total 2024</i>	<u>32,741</u>	<u>32,741</u>	

During the year ended 31 March 2025, the company incurred the following Governance costs:

£14,624 (2024 - £12,590) included in the table above.

11. Independent examiner's remuneration

The independent examiner's remuneration amounts to an independent examiner fee of £3,186 (2024 - £2,963).

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2025**

12. Staff costs

	2025 £	2024 £
Wages and salaries	24,000	24,000
Social security costs	2,057	1,234
Pension costs	533	533
	<u>26,590</u>	<u>25,767</u>

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

	2025 No.	2024 No.
	<u>1</u>	<u>1</u>

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 (2024: £24,533).

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 (2024 - £NIL).

During the year ended 31 March 2025, expenses totalling £362 were reimbursed or paid directly to 1 Trustee (2024 - £NIL to 1 Trustees) to cover expenses incurred relating to travel expense reimbursement for the Hepatic Get Together and Team Meetings.

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2025**

14. Intangible assets

	Website development t £
Cost	
At 1 April 2024	23,938
At 31 March 2025	<u>23,938</u>
Amortisation	
At 1 April 2024	23,938
At 31 March 2025	<u>23,938</u>
Net book value	
At 31 March 2025	<u><u>-</u></u>
At 31 March 2024	<u><u>-</u></u>

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2025**

15. Tangible fixed assets

	Office equipment £
Cost or valuation	
At 1 April 2024	7,538
At 31 March 2025	<u>7,538</u>
Depreciation	
At 1 April 2024	6,740
Charge for the year	204
At 31 March 2025	<u>6,944</u>
Net book value	
At 31 March 2025	<u><u>594</u></u>
At 31 March 2024	<u><u>798</u></u>

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

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2025**

16. Debtors

	2025 £	2024 £
Due within one year		
Other debtors	5,106	2,512
Prepayments and accrued income	1,043	966
	<u>6,149</u>	<u>3,478</u>
	<u><u>6,149</u></u>	<u><u>3,478</u></u>

17. Creditors: Amounts falling due within one year

	2025 £	2024 £
Trade creditors	2,970	-
Other taxation and social security	592	-
Other creditors	1,184	1,933
Accruals and deferred income	5,427	4,927
	<u>10,173</u>	<u>6,860</u>
	<u><u>10,173</u></u>	<u><u>6,860</u></u>

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

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2025**

18. Statement of funds

Statement of funds - current year

	Balance at 1 April 2024 £	Income £	Expenditure £	Transfers in/out £	Balance at 31 March 2025 £
Unrestricted funds					
General Funds - all funds	43,596	78,116	(67,087)	(18,638)	35,987
	Balance at 1 April 2024 £	Income £	Expenditure £	Transfers in/out £	Balance at 31 March 2025 £
Restricted funds					
Type 2 Pompe	3,941	695	(3,512)	-	1,124
Type 5 Mcardle	4,855	28,772	(23,870)	-	9,757
Type 3 Cori	375	-	-	(375)	-
Type 1 Van Gierke	12,775	-	-	(12,775)	-
Type 6 Hers Fund	602	-	-	(602)	-
Type 0	165	-	-	(165)	-
Better treatments and service access	-	15,633	(22,088)	6,455	-
Help with living well	7	21,183	(26,574)	5,384	-
Support across the community	224	28,683	(35,706)	6,799	-
PHD Project	61,542	-	(24,616)	-	36,926
Hepatic	-	870	(8,758)	13,917	6,029
	84,486	95,836	(145,124)	18,638	53,836
	Balance at 1 April 2024 £	Income £	Expenditure £	Transfers in/out £	Balance at 31 March 2025 £
Total of funds	128,082	173,952	(212,211)	-	89,823

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

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2025**

18. Statement of funds (continued)

Statement of funds - prior year

	<i>Balance at 1 April 2023 £</i>	<i>Income £</i>	<i>Expenditure £</i>	<i>Transfers in/out £</i>	<i>Balance at 31 March 2024 £</i>
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

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

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2025**

19. Summary of funds

Summary of funds - current year

	Balance at 1 April 2024 £	Income £	Expenditure £	Transfers in/out £	Balance at 31 March 2025 £
General funds	43,596	78,116	(67,087)	(18,638)	35,987
Restricted funds	84,486	95,836	(145,124)	18,638	53,836
	<u>128,082</u>	<u>173,952</u>	<u>(212,211)</u>	<u>-</u>	<u>89,823</u>

Summary of funds - prior year

	<i>Balance at 1 April 2023 £</i>	<i>Income £</i>	<i>Expenditure £</i>	<i>Transfers in/out £</i>	<i>Balance at 31 March 2024 £</i>
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>

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

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2025**

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.

Better treatments and service access

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

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

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2025**

19. 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.

Hepatic

Supporting people affected by hepatic GSDs

Transfers between funds

A transfer of £6,455 was made during the year from the general fund to the Better Treatments and Service Access fund, of £5,384 to the Help With Living Well fund, £6,799 to the Support Across the Community fund to cover the deficits at the year end.

Transfers of £375 from Type 3 Cori fund, £12,775 from the Type 1 Van Gierke fund, £602 from the Type 6 Hers fund and £165 from the Type 0 fund were made to the Hepatic fund. The hepatic funds have been amalgamated to recognise that funds allocated to GSD1 were intended for use across hepatic GSDs.

20. Analysis of net assets between funds

Analysis of net assets between funds - current year

	Restricted funds 2025 £	Unrestricted funds 2025 £	Total funds 2025 £
Tangible fixed assets	-	594	594
Current assets	53,917	45,485	99,402
Creditors due within one year	(81)	(10,092)	(10,173)
Total	53,836	35,987	89,823

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

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2025**

20. Analysis of net assets between funds (continued)

Analysis of net assets between funds - prior year

	<i>Restricted funds 2024 £</i>	<i>Unrestricted funds 2024 £</i>	<i>Total funds 2024 £</i>
Tangible fixed assets	-	798	798
Current assets	86,020	48,124	134,144
Creditors due within one year	(1,534)	(5,326)	(6,860)
Total	84,486	43,596	128,082

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 11 represents the contributions payable by the Charity to these funds. Included in other creditors is a balance of £81 (2024 - £104) which relates to the pension fund.

22. Related party transactions

There were no related party transactions in the year ended 31 March 2025.

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED

England & Wales - Charity number 1132271

Accounts

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.

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

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

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

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."

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

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.

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

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
(A company limited by guarantee)

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
(A company limited by guarantee)

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).

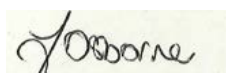
Company law requires the Trustees to prepare financial statements for each financial . Under company law, the Trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the company and of its incoming resources and application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

**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>

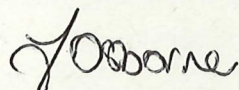
The company was entitled to exemption from audit under section 477 of the Companies Act 2006.

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
(A company limited by guarantee)

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
(A company limited by guarantee)

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
(A company limited by guarantee)

**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
------------------	------------------------

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.

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

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2024**

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.

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

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	<u>155,150</u>	<u>62,245</u>	<u>217,395</u>	<u>126,955</u>
<i>Total 2023</i>	<u>63,879</u>	<u>63,076</u>	<u>126,955</u>	

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	<u>6,248</u>	<u>15,490</u>	<u>21,738</u>	<u>15,145</u>
<i>Total 2023</i>	<u>4,594</u>	<u>10,551</u>	<u>15,145</u>	

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

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2024**

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>	

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

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2024**

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	

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

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2024**

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>	

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

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2024**

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).

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

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2024**

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.

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

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>	-

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

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>

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

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2024**

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>

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

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2024**

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

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

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2024**

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

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

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2024**

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>

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

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2024**

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.

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

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2024**

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

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

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2024**

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.

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED

England & Wales - Charity number 1132271

Accounts

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

UNAUDITED

TRUSTEES' REPORT AND FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2023

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 2023**

Trustees

Jayesh Pindolia (resigned 4 April 2022)
Nicholas Jones
Ailsa Arthur
Sarah Chikhani
Rachel Thomas
Dr Florence Osborne
Dr Charlotte Dawson (appointed 15 January 2023)
Kempton Rees (appointed 15 January 2023)

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 2023

The Trustees present their annual report together with the financial statements of the company for the 1 April 2022 to 31 March 2023. 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) 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. 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.

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

TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2023

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

The 2022-23 financial year began with work to finalise our new strategy. This is framed around the priorities identified by people affected by GSDs, through community research and a listening exercise. The resulting themes and goals 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.

A further cross-cutting theme and goal focused on organisational development was also agreed to strengthen our ability to achieve these aims:

Theme: Strong and effective organisation.

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

The strategy is underpinned by a three-year work programme, with clear progress and outcome measures to monitor our delivery and impact. The remainder of the year was focused on getting this programme underway.

Support across the community

During the year the lifting of Covid restrictions meant we were able to begin staging in-person as well as online community activities for people affected by the different types of GSD. These included in person Pompe events in Birmingham and Swansea plus an online Pompe research seminar and an online research seminar and an in-person event for those living with hepatic GSDs in Staffordshire. For people affected by McArdle's and other muscle GSDs there were online meetings for adults and for younger people and parents, as well as walking courses in Wiltshire and Pembrokeshire, with an additional families and children walking course. These events were hugely popular and provided crucial access to peer support. The easing of Covid restrictions also meant we were able to re-establish face to face support sessions in some specialist clinics.

Overall feedback received included the following:

"I have enjoyed meeting up with old friends and new ones. It is invigorating to have things in common with other people and not feel an odd one out. There was much cheerfulness in the room it gave me a happy feeling, very welcome after the last few years..."

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2023

Achievements and performance (continued)

"Thank you for yesterday's wonderful event. I was so happy to be able to come along with my mother to meet with other people with similar situations and to meet the lovely staff!... Coming along yesterday was great because everyone understood and was empathetic towards me and my mother. Was great to not have to explain my condition."

"I attended the online meeting yesterday and I'd like to say that I found it very informative. Many thanks to the organisers and presenters. The mRNA treatment for GSD3 looks very exciting in that it potentially will help other types of GSD too."

"The event was absolutely a delight and I met people who I already have a connection with. We all have Pompe - that's our connection. We don't need to say much but we understand the language of Pompe. It's so refreshing to have these get-togethers. I really appreciate AGSD-UK who organise and pay for these events."

Help with living well

Throughout the year, wide-ranging help with living well was provided by our care and welfare advisor services. Support offered spanned issues such as:

- Employment and adjustments at work
- Bereavement
- Bullying
- Legal aid
- Visa and immigration issues
- Community transport and blue badge access
- Special educational needs support
- Getting a diagnosis
- Challenging behavioural issues
- Housing and home adaptations
- Emotional support
- Medical equipment

This involved close working with multiple agencies, including social services, education, health, family support charities, housing and employers.

Advice and support was also offered in relation to financial wellbeing, including support to make successful claims for benefits such as employment and support allowance, personal independence payment, carers' allowance and disability living allowance, as well as help with securing food vouchers, food bank access, grants for domestic bills and holiday grants.

In addition we established a community support fund which enabled access to equipment and provided travel costs for low income families to AGSD-UK events.

Reported outcomes included:

- Improved wellbeing following transition to more supportive school environment
- Less worry about money
- Feeling more confidence and assured that support was available
- Increased teaching assistant support
- Improved social care package
- Improved housing situation
- Securing respite care

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2023

Achievements and performance (continued)

The following comments are typical of the universally positive feedback received:

- “I was recently diagnosed with Late Onset Pompe Disease, which has come as a huge shock to me. I am struggling daily to come to terms with both my physical and mental symptoms. I desperately needed help and guidance and...AGSD have been absolutely wonderful in supporting me at this really difficult time with both practical and emotional support...”
- “I appreciate the incredible work that you do at AGSD for people like myself. You give hope when it feels like there's none left and the strength to fight when it's so easy to just give up! The work that you guys do, going above and beyond to get justice for people that have been let down continuously is applaudable. Thank you for making us feel that we are not alone. Thank you for your care and compassion.”
- “As a result of your continuous support, I will now be receiving the enhanced mobility payment; this will help me greatly.”
- “Just wanted to say a big thank you for your guidance about finding work...I was struggling to find a suitable position and was starting to feel unemployable. As a result I secured myself a position with a company that accepted my situation and it's given me a boost to my confidence being back in employment.”

Alongside our advisory services, our regular magazine Glisten continued to reach over 1500 people, sharing latest updates on research and managing the condition, together with personal experiences and practical tips. Meanwhile our website hosting information on all GSDs and signposting further support was visited 42,948 times.

Better treatments and service access

Over the course of the year the charity was involved in building the evidence base around GSDs, helping to recruit community members for a range of studies looking at the experience of people affected by different variants and gaining feedback from people living with the condition to help shape study design and information for research participants.

Having contributed to the National Institute for Health and Care Excellence' review of *avalglucosidase alfa* for treatment of people affected by Pompe, AGSD-UK gathered and submitted further evidence for the NICE appraisal of *cipaglucosidase alfa* with *miglustat* and nominated and supported a patient expert to contribute to the review. Given the varying responses to therapy among people affected, we are pleased that, following recommendations by NICE, both of these additional Pompe treatment options are now being made available to community members.

We also continued to convene meetings of specialist professionals to enable them to share expertise and work together to improve management of the condition and collaborated with other rare condition organisation to press for early diagnosis and better treatment and services.

Strong and effective organisation

During the year we were pleased to welcome two new trustees - Dr Charlotte Dawson and Kempton Rees, bringing experience and expertise in key areas identified by our trustee skills audit.

We began the process of benchmarking our organisation against recognised charity standards, in order to identify ways to strengthen our governance and performance.

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2023

Achievements and performance (continued)

Meanwhile, working remotely our through our small team, we continued to manage costs carefully, whilst offering more face to face support and events as we emerged from Covid. As always, we were extremely grateful for the support of our dedicated volunteers who bring considerable extra capacity to our activities.

Finance, fundraising and future plans

Moving forward we will continue with delivery of our three year plan, in support of our strategy goals. In addition to our core services, planned activities for the period April 2023-March 2024 include; staging a full scale weekend community event, developing an online self management programme and establishing access to a range of therapeutic activities online.

We will continue to pursue additional funding to support these activities, with a focus on increased community fundraising, as well as expanding valued grant income from trusts and industry partners.

Our gratitude goes to all those committed individuals and organisational partners who have supported our work though their fundraising and charitable donations over the year, including Amicus, Astellas, Albert Hunt Trust, Beam, Sanofi Genzyme, Spark Therapeutics, Ultragenyx and Vitaflo. Their ongoing support is crucial in enabling us to deliver the priorities identified by people living with this extremely complex and challenging condition and is very much appreciated.

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 £24,159 which is an increase from the previous year (£23,462). The trustees' future focus will be on increasing income while tightly managing costs. The total restricted funds is now £59,194 (2022: £72,936).

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 £1,014. Our free reserves at 31 March 2023 are therefore £23,145.

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2023

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.

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.

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

TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2023

Structure, governance and management (continued)

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 2023

Statement of Trustees' responsibilities

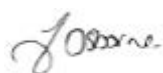
The Trustees (who are also the directors of the company for the purposes of company law) are responsible for preparing the Trustees' report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

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 December 2023 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 2023**

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 2023.

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

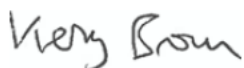
I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe:

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: 22 December 2023

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
(A company limited by guarantee)

**STATEMENT OF FINANCIAL ACTIVITIES (INCORPORATING INCOME AND EXPENDITURE ACCOUNT)
FOR THE YEAR ENDED 31 MARCH 2023**

	Note	Restricted funds 2023 £	Unrestricted funds 2023 £	Total funds 2023 £	Total funds 2022 £
Income from:					
Donations and legacies	4	63,879	63,076	126,955	107,280
Other trading activities	5	4,614	11,371	15,985	17,455
Investments	6	-	451	451	14
Other income	7	-	325	325	7,000
Total income		68,493	75,223	143,716	131,749
Expenditure on:					
Charitable activities		83,674	73,087	156,761	144,848
Total expenditure		83,674	73,087	156,761	144,848
Net (expenditure)/income		(15,181)	2,136	(13,045)	(13,099)
Transfers between funds	17	1,439	(1,439)	-	-
Net movement in funds		(13,742)	697	(13,045)	(13,099)
Reconciliation of funds:					
Total funds brought forward		72,936	23,462	96,398	109,497
Total funds carried forward		59,194	24,159	83,353	96,398

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

The notes on pages 13 to 31 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 2023

	Note	2023 £	2022 £
Fixed assets			
Intangible assets	13	-	4,789
Tangible assets	14	1,014	1,133
		<u>1,014</u>	<u>5,922</u>
Current assets			
Debtors	15	6,865	5,771
Cash at bank and in hand		81,619	89,950
		<u>88,484</u>	<u>95,721</u>
Creditors: amounts falling due within one year	16	(6,145)	(5,245)
Total net assets		<u><u>83,353</u></u>	<u><u>96,398</u></u>
Charity funds			
Restricted funds	17	59,194	72,936
Unrestricted funds	17	24,159	23,462
Total funds		<u><u>83,353</u></u>	<u><u>96,398</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 December 2023 and signed on their behalf by:



Dr Florence Osborne
Chair

The notes on pages 13 to 31 form part of these financial statements.

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

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2023

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
(A company limited by guarantee)

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2023**

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
(A company limited by guarantee)

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2023**

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 2023**

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 £59,396 (2022: £57,225). This is based on the open market value of benefits received.

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2023**

4. Income from donations and legacies

	Restricted funds 2023 £	Unrestricted funds 2023 £	Total funds 2023 £	<i>Total funds 2022 £</i>
Donations	367	6,430	6,797	5,754
Grants	48,500	11,000	59,500	40,914
Donations in kind	15,012	44,384	59,396	57,225
Gift aid	-	1,262	1,262	3,387
Total 2023	<u>63,879</u>	<u>63,076</u>	<u>126,955</u>	<u>107,280</u>
<i>Total 2022</i>	<u>38,889</u>	<u>68,391</u>	<u>107,280</u>	

5. Income from other trading activities

Income from fundraising events

	Restricted funds 2023 £	Unrestricted funds 2023 £	Total funds 2023 £	<i>Total funds 2022 £</i>
Fundraising events	4,594	10,551	15,145	16,438
<i>Total 2022</i>	<u>1,185</u>	<u>15,253</u>	<u>16,438</u>	

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2023**

5. Income from other trading activities (continued)

Income from non charitable trading activities

	Restricted funds 2023 £	Unrestricted funds 2023 £	Total funds 2023 £	<i>Total funds 2022 £</i>
Subscriptions	-	800	800	945
Book Sales	20	20	40	72
Total 2023	<u>20</u>	<u>820</u>	<u>840</u>	<u>1,017</u>
<i>Total 2022</i>	<u>66</u>	<u>951</u>	<u>1,017</u>	

6. Investment income

	Unrestricted funds 2023 £	Total funds 2023 £	<i>Total funds 2022 £</i>
Investment income	<u>451</u>	<u>451</u>	<u>14</u>
<i>Total 2022</i>	<u>14</u>	<u>14</u>	

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2023**

7. Other incoming resources

	Restricted funds 2023 £	Unrestricted funds 2023 £	Total funds 2023 £	Total funds 2022 £
Other income	-	325	325	7,000
<i>Total 2022</i>	<i>7,000</i>	-	<i>7,000</i>	

8. Analysis of grants

	Grants 2023 £	Total funds 2023 £	Total funds 2022 £
Grants	273	273	1,090
<i>Total 2022</i>	<i>1,090</i>	<i>1,090</i>	

In 2023 no grants were given to institutions (2022: 0) and 2 to individuals (2022: 5).

9. Analysis of expenditure by activities

	Activities undertaken directly 2023 £	Grant funding of activities 2023 £	Support costs 2023 £	Total funds 2023 £	Total funds 2022 £
Charitable activities	123,205	273	33,283	156,761	144,848
<i>Total 2022</i>	<i>96,930</i>	<i>1,090</i>	<i>46,828</i>	<i>144,848</i>	

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2023**

9. Analysis of expenditure by activities (continued)

Analysis of direct costs

	Total funds 2023 £	<i>Total funds 2022 £</i>
Walking course	6,709	-
Consultancy	59,396	56,725
Travel and accommodation expenses	3,095	277
Staff costs	22,408	14,273
Freelancer consulting costs	29,434	25,655
Patient and Family meetings	2,163	-
	123,205	96,930

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2023**

9. Analysis of expenditure by activities (continued)

Analysis of support costs

	Total funds 2023 £	<i>Total funds 2022 £</i>
Rent	312	312
Office costs	396	3,316
Online services	968	493
Website and computer costs	8,628	9,827
Sundry expenses	-	65
Subscriptions	138	174
Insurance	717	793
Printing, post and stationery	1,578	4,173
Fundraising	(43)	369
Depreciation - office equipment	288	378
Amortisation - website development	4,789	4,787
Accountancy & payroll	9,827	7,193
Consultancy	-	6,500
Staff training	787	-
Independent examiners fee	2,773	2,593
Staff costs	2,125	5,855
Total 2023	33,283	46,828

During the year ended 31 March 2023, the company incurred the following Governance costs:

£12,600 (2022 - £9,786) included within the table above.

10. Independent examiner's remuneration

The independent examiner's remuneration amounts to an independent examiner fee of £2,773 (2022 - £2,593).

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2023**

11. Staff costs

	2023	2022
	£	£
Wages and salaries	24,000	19,777
Pension costs	533	351
	<u>24,533</u>	<u>20,128</u>

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

2023	2022
No.	No.
<u>1</u>	<u>1</u>

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 (2022: £14,801).

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 (2022 - £NIL).

During the year ended 31 March 2023, expenses totalling £938 were reimbursed or paid directly to 2 Trustees (2022 - £562 to 1 Trustees) to cover expenses incurred relating to postage and a walking course.

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2023**

13. Intangible assets

	Website development t £
Cost	
At 1 April 2022	23,938
At 31 March 2023	23,938
Amortisation	
At 1 April 2022	19,149
Charge for the year	4,789
At 31 March 2023	23,938
Net book value	
At 31 March 2023	-
<i>At 31 March 2022</i>	4,789

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2023**

14. Tangible fixed assets

	Office equipment £
Cost or valuation	
At 1 April 2022	7,369
Additions	169
At 31 March 2023	7,538
Depreciation	
At 1 April 2022	6,236
Charge for the year	288
At 31 March 2023	6,524
Net book value	
At 31 March 2023	1,014
<i>At 31 March 2022</i>	1,133

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2023**

15. Debtors

	2023 £	2022 £
Due within one year		
Trade debtors	5,674	5,002
Other debtors	50	50
Prepayments and accrued income	1,141	719
	<u>6,865</u>	<u>5,771</u>

16. Creditors: Amounts falling due within one year

	2023 £	2022 £
Other creditors	2,474	1,266
Accruals and deferred income	3,671	3,979
	<u>6,145</u>	<u>5,245</u>

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2023**

17. Statement of funds

Statement of funds - current year

	Balance at 1 April 2022 £	Income £	Expenditure £	Transfers in/out £	Balance at 31 March 2023 £
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

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2023**

17. Statement of funds (continued)

Statement of funds - prior year

	<i>Balance at 1 April 2021 £</i>	<i>Income £</i>	<i>Expenditure £</i>	<i>Transfers in/out £</i>	<i>Balance at 31 March 2022 £</i>
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

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2023**

18. Summary of funds

Summary of funds - current year

	Balance at 1 April 2022 £	Income £	Expenditure £	Transfers in/out £	Balance at 31 March 2023 £
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>

Summary of funds - prior year

	<i>Balance at 1 April 2021 £</i>	<i>Income £</i>	<i>Expenditure £</i>	<i>Transfers in/out £</i>	<i>Balance at 31 March 2022 £</i>
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>

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2023**

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.

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2023**

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.

Transfers between funds

A transfer of £1,439 was made during the year from the general fund to the Help with living well fund to cover the deficit at the year end.

19.

Analysis of net assets between funds - current year

	Restricted funds 2023 £	Unrestricted funds 2023 £	Total funds 2023 £
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

Analysis of net assets between funds - prior year

	<i>Restricted funds 2022 £</i>	<i>Unrestricted funds 2022 £</i>	<i>Total funds 2022 £</i>
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

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2023

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 £107 (2022 - £107) which relates to the pension fund.

21. Related party transactions

There were no related party transactions in the year ended 31 March 2023.

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED

England & Wales - Charity number 1132271

Accounts

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
(A company limited by guarantee)

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."

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

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
(A company limited by guarantee)

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.

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

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
(A company limited by guarantee)

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
(A company limited by guarantee)

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:

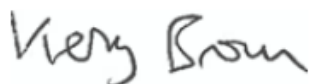
1. accounting records were not kept in respect of the company as required by section 386 of the 2006 Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts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

**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
(A company limited by guarantee)

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.

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

**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
---------------------	----------------------

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

**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
------------------	------------------------

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
(A company limited by guarantee)

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.

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

**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
(A company limited by guarantee)

**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>	

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

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>	

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

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
<i>Total 2021</i>	94,030	2,520	43,146	139,696	

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

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	-
	96,930	<i>94,030</i>

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

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).

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

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

12. Staff costs

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

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

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

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.

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

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

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>

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

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

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>

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

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

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>
	<u>5,771</u>	<u><i>11,915</i></u>

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>
	<u>5,245</u>	<u><i>8,749</i></u>

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

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

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

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

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

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

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>

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

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

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>

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

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

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.

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

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

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	<u>72,936</u>	<u>23,462</u>	<u>96,398</u>

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	<u>82,196</u>	<u>27,301</u>	<u>109,497</u>

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

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

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.

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED

England & Wales - Charity number 1132271

Accounts

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

UNAUDITED

TRUSTEES' REPORT AND FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2021

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 2021**

Trustees

Jayesh Pindolia
Nicholas Jones
Ailsa Arthur
Robert Seaborne (resigned 31 July 2021)
Sarah Chikhani (appointed 22 July 2020)
Rachel Thomas (appointed 22 July 2020)
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 2021

The Trustees present their annual report together with the financial statements of the company for the 1 April 2020 to 31 March 2021. 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
(A company limited by guarantee)

TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2021

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

2020 has not been an easy year for the charity sector. This has been well publicised in the media. Despite this the AGSD-UK has remained strong and has continued to provide support to the GSD community.

Our 2020 conference was cancelled and replaced by the highly successful online Winter Season. All members of the community took part with presentations from health professionals, researchers, information on diet and patients life stories. It is still available to view on the charities' YouTube channel. Woven into this were meet-ups online with coffee mornings, children's quizzes and competitions, keeping up the spirits when no-one was able to meet up in person. A similar format will take place this year {2020 and spilling over into 2021} due to uncertainty over the pandemic. It is sincerely hoped that 2022 will see the return of the annual conference and face to face meetings.

The pandemic has resulted in a 40% increase in requests for help. This included requests for advice about shielding, accommodation, shopping and supplies. Several letters were written to MPs and to local government seeking access to support for members of our community.

Requests for grants similarly increased. For example, applications were made for urgent home adaptations to ensure independent living without the need for daily carers.

There was a 40% increased demand for benefit cheques and help with filling out forms such as PIP, Daily Living Allowance, Universal Credit and Employment Support Allowance.

To support mental health members were offered an online mental wellbeing course in response to many requests for help. A mental health booklet was produced by Ben Parker, a member of our Pompe Support Team. This has been much acclaimed and reprints have been sought internationally.

A COVID-19 advice area was created on the website. This was well received by the community members, industry and professionals.

Time was devoted to developing online support. For example, weekly coffee mornings and advice surrounding virtual hospital appointments. Tune in Tuesdays, hosted by volunteer Gemma Seyfrang proved a great success. During lockdown the Pompe Support Team wanted to create a fun opportunity for children with the avatar competition. The drawings were used to create a tea towel which are still available to buy.

Volunteer Andrew Wakelin was featured in the National Magazine. In the article Andrew talks about his lifetime love of walking and the Walking with McArdle's courses. Andrew has been organising and leading for over ten years and helped many people.

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

TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2021

Achievements and performance (continued)

The charity was lucky enough to support Lisa Massimo through two weeks of work experience, while she completed her MSc in Genetic Counselling. She became involved in the Pompe community, learning about the difficulties that surround obtaining genetic support.

This year has seen the application of a new drug for Pompe, Avalglucosidase-alfa, seeking approval through NICE. Advice on living with the disease from NICE was sought through the AGSD-UK. We were delighted to collaborate with MDUK, MSUK and Genetic Alliance. Luke Fraser and Kempton Rees represented the charity at the NICE scoping process. Further work and collaboration are taking place to ensure the charity is ready for the appraisal process of avalglucosidase and a further drug, recently developed for Pompe, Cipaglucosidase.

The AGSD-UK has continued to host the hepatic guidelines meetings. Consultants, Clinical Nurse Specialists and Dietitians from throughout the UK are all invited to discuss anything concerned with hepatic gsds. These are lively and well attended where case studies, research and best practise are all talked through and problems are posed and answers found.

Staff

Moving beyond the year covered in the report there has been an increase in the number of staff employed. Val Buxton has joined us a part time employee and all other staff now work for us on a self-employed freelance basis. This has ameliorated one of the charity's key risks; loss of key personnel. We welcome Vicki Lucass who as our winter season producer but has now taken on the extra role of charity coordinator.

Elizabeth Davenport has recently joined us bringing with her many years of experience as a charity families advocate. She will now take over part of the role of the Specialist Care Advisor.

Zainab Hussain is another new face and will be taking on the role of benefits advisor. This is an area she brings many years of skill and experience to. She will be replacing Julie Jackson, who is stepping down as our current benefits advisor. We are sad to see Julie go who had a 100% success rate in all benefits appeals. The appeals process is challenging and anxiety inducing for claimants. Julie calmly supported people through their submissions and was always on the receiving end of much praise and thanks. Our gratitude and best wishes for the future go out to her.

We are delighted that Jackie Henson has taken on some extra duties. In addition to her role in finance she is now responsible for administration and areas of the website as our Charity Officer.

Jane Lewthwaite is stepping away from her full-time contract to work freelance and consequently reduced hours. The trustees cannot thank Jane enough for her steadfastness and dedication to the charity during the pandemic. Despite the step back, Jane is still very much involved with and a supporter of the charity.

September 2021 saw the appointment of our CEO, Val Buxton. The trustees are delighted to welcome her. She has an extensive background in the health and charities sectors, working at a senior level to improve policy and services. She will use this experience to ensure that the hard work that has built the AGSD-UK is used as a foundation to grow the charity and allow it to thrive.

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2021

Achievements and performance (continued)

Fundraising

We want to thank everyone who has contributed to fundraising. Our community has continued to raise money for the charity during the pandemic, not an easy task. Our thanks go to:-

Eileen Rice
Ashley Eustace
Lynn Sharman
Bedford Park Masonic H Find
Gemma Seyfrang and Kieran Stubbings
Frank and Irene Green
Grant Fraser
Nigel Walker
Jennifer Wood
Sonia Worthy
Dawn Fitzroy
Lucy Moran
Simon Atewell
Georgie Thompson
Sylvia Wilson
Nikki Christie
Media 10 in memory of Louise Bett
Flo Osborne

We also wish to thank the volunteers who have put in many hours of work. Our immense gratitude for their hard work and dedication. The time that is put in from professionals and volunteers is included as benefit-in-kind. Each year it can total around £60,000

Our thanks go for the continued support from Industry, Foundations and Trusts. This includes:-

Amicus
Astellas/Audentes
Avro Bio
Edward Gostling Foundation
FMR Global Health
Sangomo
Sanofi Genzyme
Spark Therapeutics
Ultragenyx
Vitaflo

Finance

It can be seen that grants from industry have dropped this year. This can be accounted for in the main, by the cancellation of the annual face to face conference and replaced by an on-line conference. Grants from industry reflected the smaller costs of the virtual conference. Grants for patient support, education and community engagement continue to be sought and given.

Savings have been made this year as staff work from home and travel and face to face meetings have been cut to a minimum in line with the government guidelines issued during the pandemic. The charity's finances remain in a robust position.

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2021

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 £27,301 which is an increase from the previous year (£16,548). The trustees' future focus will be on increasing income while tightly managing costs.

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

c. Investment policy and performance

The Association holds 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.

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2021

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 Charity Director and any other staff plus a range of volunteers.

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

d. Pay policy for key management personnel

The company currently has one permanent member of staff – the Specialist Care Advisor, and moving beyond the year covered in the report there has been an increase in the number of staff employed to include three part-time members of staff.

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

e. Risk Management

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

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

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

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

TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2021

Plans for future periods

In relation to 2021-22, as with the previous financial year both costs and funding for face to face activities have reduced, and we are looking at similar overall levels of income and expenditure.

Looking forward, we're working to develop a new 3 year strategy built on the priorities of the AGSD community to help us better engage with potential funders. The strong relationship with the treatment industry is continuing and work on promising new therapies offers scope for further partnerships and funding to support shared goals. Though funding for core costs remains challenging, our fixed costs are limited and we'll ensure overheads are properly reflected in project funding bids and use the new strategy to underpin a systematic approach to trust funders for further support.

For 2022 -23 we expect to see some uplift in funding and expenditure to reflect an increase in face to face activities, with the expectation of some growth in both income and expenditure in the years ahead.

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:

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 2021**

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 2021.

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

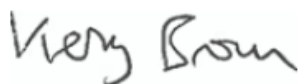
I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe:

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:

28 January 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
(A company limited by guarantee)

**STATEMENT OF FINANCIAL ACTIVITIES (INCORPORATING INCOME AND EXPENDITURE ACCOUNT)
FOR THE YEAR ENDED 31 MARCH 2021**

	Note	Restricted funds 2021 £	Unrestricted funds 2021 £	Total funds 2021 £	<i>Total funds 2020 £</i>
Income from:					
Donations and legacies	4	25,794	79,788	105,582	184,996
Other trading activities	5	1,784	12,956	14,740	20,644
Investments	6	-	42	42	154
Other income	7	1,053	1,464	2,517	8
		<u>28,631</u>	<u>94,250</u>	<u>122,881</u>	<u>205,802</u>
Total income					
Expenditure on:					
Raising funds	8	1,972	-	1,972	4,152
Charitable activities		56,199	83,497	139,696	212,982
		<u>58,171</u>	<u>83,497</u>	<u>141,668</u>	<u>217,134</u>
Total expenditure					
		<u>(29,540)</u>	<u>10,753</u>	<u>(18,787)</u>	<u>(11,332)</u>
Net movement in funds					
Reconciliation of funds:					
Total funds brought forward		111,736	16,548	128,284	139,616
		<u>82,196</u>	<u>27,301</u>	<u>109,497</u>	<u>128,284</u>
Total funds carried forward					

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 2021

	Note	2021 £	2020 £
Fixed assets			
Intangible assets	14	9,577	14,364
Tangible assets	15	1,511	2,180
		<u>11,088</u>	<u>16,544</u>
Current assets			
Debtors	16	11,915	19,691
Cash at bank and in hand		95,243	98,194
		<u>107,158</u>	<u>117,885</u>
Creditors: amounts falling due within one year	17	(8,749)	(6,145)
Total net assets		<u><u>109,497</u></u>	<u><u>128,284</u></u>
Charity funds			
Restricted funds	18	82,196	111,736
Unrestricted funds	18	27,301	16,548
Total funds		<u><u>109,497</u></u>	<u><u>128,284</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 28 January 2022 and signed on their behalf by:

Nicholas Jones
Trustee



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)

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2021

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.

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

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2021**

2. Accounting policies (continued)

2.4 Expenditure (continued)

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

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

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

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

2.5 Cash flow

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

2.6 Intangible assets and amortisation

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

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

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

The estimated useful lives are as follows:

Amortisation is provided on the following basis:

Website development	- 20 % straight line
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ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
(A company limited by guarantee)

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2021**

2. Accounting policies (continued)

2.7 Tangible fixed assets and depreciation

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

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

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

Depreciation is provided on the following basis:

Office equipment	- 25% reducing balance
------------------	------------------------

2.8 Financial instruments

Debtors

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

Creditors

Short term trade creditors are measured at transaction price.

Cash

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

There are no complex financial instruments.

2.9 Pensions

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

2.10 Fund accounting

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

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

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

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2021**

2. Accounting policies (continued)

2.11 Role of Volunteers

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

3. Critical accounting estimates and areas of judgment

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

Critical areas of judgment:

- (i) Donations of consulting by Andrew Wakelin
- (ii) Donations of conference guest speakers
- (iii) Donations of services including printing, graphic design, meeting rooms and consultant attendance of events

In accordance with the Charities SORP FRS 102, the charity has valued the benefit it receives from donated services as £53,416 (2020: £47,540). This is based on the open market value of benefits received.

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

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2021**

4. Income from donations and legacies

	Restricted funds 2021 £	Unrestricted funds 2021 £	Total funds 2021 £	<i>Total funds 2020 £</i>
Donations	970	7,781	8,751	10,155
Legacies	-	-	-	93
Grants	20,618	20,190	40,808	125,824
Donations in kind	4,206	49,210	53,416	47,540
Gift aid	-	2,607	2,607	1,384
	<u>25,794</u>	<u>79,788</u>	<u>105,582</u>	<u>184,996</u>
<i>Total 2020</i>	<u>132,783</u>	<u>52,213</u>	<u>184,996</u>	

5. Income from other trading activities

Income from fundraising events

	Restricted funds 2021 £	Unrestricted funds 2021 £	Total funds 2021 £	<i>Total funds 2020 £</i>
Fundraising events	1,716	11,739	13,455	10,251
	<u>11</u>	<u>10,240</u>	<u>10,251</u>	
<i>Total 2020</i>	<u>11</u>	<u>10,240</u>	<u>10,251</u>	

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

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2021**

5. Income from other trading activities (continued)

Income from non charitable trading activities

	Restricted funds 2021 £	Unrestricted funds 2021 £	Total funds 2021 £	<i>Total funds 2020 £</i>
Conference	-	-	-	4,088
Subscriptions	-	1,174	1,174	1,315
Book Sales	68	43	111	70
Walking courses	-	-	-	4,920
Total 2021	<u>68</u>	<u>1,217</u>	<u>1,285</u>	<u>10,393</u>
<i>Total 2020</i>	<u>4,957</u>	<u>5,436</u>	<u>10,393</u>	

6. Investment income

	Unrestricted funds 2021 £	Total funds 2021 £	<i>Total funds 2020 £</i>
Investment income	<u>42</u>	<u>42</u>	<u>154</u>
<i>Total 2020</i>	<u>154</u>	<u>154</u>	

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

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2021**

7. Other incoming resources

	Restricted funds 2021 £	Unrestricted funds 2021 £	Total funds 2021 £	<i>Total funds 2020 £</i>
Other income	1,053	1,464	2,517	8
<i>Total 2020</i>	8	-	8	

8. Expenditure on raising funds

Costs of raising voluntary income

	Restricted funds 2021 £	Unrestricted funds 2021 £	Total funds 2021 £	<i>Total funds 2020 £</i>
Fundraising Expenses	1,972	-	1,972	4,152
<i>Total 2020</i>	-	4,152	4,152	

9. Analysis of grants

	Grants 2021 £	Total funds 2021 £	<i>Total funds 2020 £</i>
Grants	2,520	2,520	950
<i>Total 2020</i>	950	950	

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

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2021**

9. Analysis of grants (continued)

In 2021 no grants were given to institutions (2020: 0) and 15 to individuals (2020: 4).

10. Analysis of expenditure by activities

	Activities undertaken directly 2021 £	Grant funding of activities 2021 £	Support costs 2021 £	Total funds 2021 £	<i>Total funds 2020 £</i>
Charitable activities	94,030	2,520	43,146	139,696	212,982
<i>Total 2020</i>	115,504	950	96,528	212,982	

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2021**

10. Analysis of expenditure by activities (continued)

Analysis of direct costs

	Total funds 2021 £	<i>Total funds 2020 £</i>
Conference	5,914	26,269
Walking course	-	5,395
Consultancy	51,916	39,540
Travel and accommodation expenses	-	10,059
Staff costs	36,200	34,241
	94,030	<i>115,504</i>

Analysis of support costs

	Total funds 2021 £	<i>Total funds 2020 £</i>
Rent	312	3,019
Office costs	2,622	8,556
Online services	396	644
Website and computer costs	10,176	11,110
Sundry expenses	2,418	3,709
Subscriptions	352	197
Insurance	815	675
Printing, post and stationery	5,595	7,540
Fundraising	278	-
Currency gains/losses	246	(314)
Depreciation - office equipment	669	726
Amortisation - website development	4,787	4,787
Accountancy & payroll	11,264	7,922
Independent examiners fee	2,419	2,321
Staff costs	797	45,636
	43,146	<i>96,528</i>

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

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2021**

10. Analysis of expenditure by activities (continued)

Analysis of support costs (continued)

During the year ended 31 March 2021, the company incurred the following Governance costs:

£13,683 (2020 - £10,405) included within the table above.

11. Independent examiner's remuneration

The independent examiner's remuneration amounts to an independent examiner fee of £2,419 (2020 - £2,321).

12. Staff costs

	2021	<i>2020</i>
	£	£
Wages and salaries	36,200	74,741
Social security costs	-	3,925
Pension costs	797	1,211
	36,997	79,877

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

2021	<i>2020</i>
No.	No.
1	2

The key management personnel of the charity are the Trustees and Development Director. Total employee benefits of key management personnel of the charity were £NIL (2020: £34,318).

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 (2020 - £NIL).

During the year ended 31 March 2021, no Trustee expenses have been incurred (2020 - £NIL).

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2021**

14. Intangible assets

	Website development £
Cost	
At 1 April 2020	23,938
At 31 March 2021	<u>23,938</u>
Amortisation	
At 1 April 2020	9,574
Charge for the year	4,787
At 31 March 2021	<u>14,361</u>
Net book value	
At 31 March 2021	<u>9,577</u>
<i>At 31 March 2020</i>	<u><u>14,364</u></u>

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2021**

15. Tangible fixed assets

	Office equipment £
Cost or valuation	
At 1 April 2020	7,369
At 31 March 2021	<u>7,369</u>
Depreciation	
At 1 April 2020	5,189
Charge for the year	669
At 31 March 2021	<u>5,858</u>
Net book value	
At 31 March 2021	<u><u>1,511</u></u>
<i>At 31 March 2020</i>	<u><u>2,180</u></u>

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2021**

16. Debtors

	2021 £	<i>2020</i> £
Due within one year		
Trade debtors	9,275	<i>18,205</i>
Other debtors	50	<i>-</i>
Prepayments and accrued income	2,590	<i>1,486</i>
	11,915	<i>19,691</i>

17. Creditors: Amounts falling due within one year

	2021 £	<i>2020</i> £
Trade creditors	2,406	<i>318</i>
Other taxation and social security	-	<i>891</i>
Other creditors	1,622	<i>1,123</i>
Accruals and deferred income	4,721	<i>3,813</i>
	8,749	<i>6,145</i>

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

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2021**

18. Statement of funds

Statement of funds - current year

	Balance at 1 April 2020 £	Income £	Expenditure £	Balance at 31 March 2021 £
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

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

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2021**

18. Statement of funds (continued)

Statement of funds - prior year

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

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

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2021**

19. Summary of funds

Summary of funds - current year

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

Summary of funds - prior year

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

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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.

Transfer between funds

The transfer in 2020 out of the Patient Education and Empowerment Fund represents event costs misallocated to general funds in prior years. These amounts have been transferred to unrestricted funds.

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20. Analysis of net assets between funds

Analysis of net assets between funds - current year

	Restricted funds 2021 £	Unrestricted funds 2021 £	Total funds 2021 £
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

Analysis of net assets between funds - prior year

	<i>Restricted funds 2020 £</i>	<i>Unrestricted funds 2020 £</i>	<i>Total funds 2020 £</i>
Tangible fixed assets	-	2,180	2,180
Intangible fixed assets	-	14,364	14,364
Current assets	112,190	5,695	117,885
Creditors due within one year	(454)	(5,691)	(6,145)
Total	111,736	16,548	128,284

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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. Operating lease commitments

At 31 March 2021 the company had commitments to make future minimum lease payments under non-cancellable operating leases as follows:

	2021	<i>2020</i>
	£	£
Land and buildings		
Not later than 1 year	-	312
	<u> </u>	<u> </u>

23. Related party transactions

There were no related party transactions in the year ended 31 March 2021.