

Registered number: 06981121
Charity number: 1132271

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

UNAUDITED

TRUSTEES' REPORT AND FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2023

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

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

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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..."

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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

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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.

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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.

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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.

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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

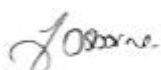
The Trustees (who are also the directors of the company for the purposes of company law) are responsible for preparing the Trustees' report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

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
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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

Kerry Brown

FCA

Crowe U.K. LLP

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

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

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NOTES TO THE FINANCIAL STATEMENTS
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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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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.

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2. Accounting policies (continued)

2.11 Role of Volunteers

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

3. Critical accounting estimates and areas of judgment

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

Critical accounting estimates and assumptions:

Critical areas of judgment:

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

In accordance with the Charities SORP FRS 102, the charity has valued the benefit it receives from donated services as £59,396 (2022: £57,225). This is based on the open market value of benefits received.

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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>	

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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	451	451	14
<i>Total 2022</i>	<u>14</u>	<u>14</u>	

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7. Other incoming resources

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

8. Analysis of grants

	Grants 2023 £	Total funds 2023 £	<i>Total funds 2022 £</i>
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 £	<i>Total funds 2022 £</i>
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>	

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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	-
	<hr/> 123,205 <hr/>	<hr/> 96,930 <hr/>

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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).

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11. Staff costs

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

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

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

The key management personnel of the charity are the Trustees and Chief Executive. Total employee benefits of key management personnel of the charity were £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.

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13. Intangible assets

	Website developmen 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

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14. Tangible fixed assets

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

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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
	6,865	5,771

16. Creditors: Amounts falling due within one year

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

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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
	<u>72,936</u>	<u>68,493</u>	<u>(83,674)</u>	<u>1,439</u>	<u>59,194</u>
Total of funds	<u><u>96,398</u></u>	<u><u>143,716</u></u>	<u><u>(156,761)</u></u>	<u><u>-</u></u>	<u><u>83,353</u></u>

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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
	<u>82,196</u>	<u>47,140</u>	<u>(56,635)</u>	<u>235</u>	<u>72,936</u>
Total of funds	<u><u>109,497</u></u>	<u><u>131,749</u></u>	<u><u>(144,848)</u></u>	<u><u>-</u></u>	<u><u>96,398</u></u>

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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>

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18. Summary of funds (continued)

Restricted Funds

Type 2 Pompe's

Supporting GSD Type 2, Pompe.

Type 5 McArdles

Supporting GSD Type 5, McArdle.

Type 3 Cori

Supporting GSD Type 3, Cori.

Type 1 Von Gierke

Supporting GSD Type 1, Von Gierke.

Type 6 Hers Fund

Supporting GSD Type 6, Hers.

Hardship Fund

Supporting patients and families suffering hardship.

Conferences

Supporting AGSD-UK Annual conference.

Medical Advisory Board

Supporting meetings of AGSD-UK Medical Advisors.

Specialist Care Advisor

Supporting the provision of a Pompe patient support worker.

Type 0

Supporting GSD Type 0.

Patient Education and Empowerment

Supporting patients and families by providing family days.

Better treatments and service access

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

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18. Summary of funds (continued)

Help with living well

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

Support across the community

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

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

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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.