

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 2021**

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**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)**

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**REFERENCE AND ADMINISTRATIVE DETAILS OF THE COMPANY, ITS TRUSTEES AND ADVISERS**  
**FOR THE YEAR ENDED 31 MARCH 2021**

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**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

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

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**TRUSTEES' REPORT**  
**FOR THE YEAR ENDED 31 MARCH 2021**

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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.

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

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**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.

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

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**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, Cipalglucosidase.

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.

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

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**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.

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

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**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.



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

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**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.

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

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**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

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

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**INDEPENDENT EXAMINER'S REPORT**  
**FOR THE YEAR ENDED 31 MARCH 2021**

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**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:

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 2021**

	Note	Restricted funds 2021 £	Unrestricted funds 2021 £	Total funds 2021 £	Total funds 2020 £
<b>Income from:</b>					
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>
<b>Total income</b>					
<b>Expenditure on:</b>					
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>
<b>Total expenditure</b>					
		<u>(29,540)</u>	<u>10,753</u>	<u>(18,787)</u>	<u>(11,332)</u>
<b>Net movement in funds</b>					
<b>Reconciliation of funds:</b>					
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>
<b>Total funds carried forward</b>					

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

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:

**Nicholas Jones**  
Trustee

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

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

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**1. General information**

**1.1 Company Status**

The Association for Glycogen Storage Disease (UK) Limited is a company limited by guarantee in England, whose registered office is Black Country House, Rounds Green Road, Oldbury, West Midlands, B29 2DG. The company's registered number is 06981121. In the event of the company being wound up, the liability in respect of the guarantee is limited to £10 per member of the company.

**2. Accounting policies**

**2.1 Basis of preparation of financial statements**

The financial statements have been prepared in accordance with the Charities SORP (FRS 102) - Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) and the Companies Act 2006.

Association for Glycogen Storage Disease (UK) Limited meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy.

**2.2 Going concern**

The trustees have a reasonable expectation that the company has adequate resources to continue in operational existence for the foreseeable future. They continue to believe the going concern basis of accounting appropriate in preparing the annual financial statements.

**2.3 Income**

All income is recognised once the company has entitlement to the income, it is probable that the income will be received and the amount of income receivable can be measured reliably.

Income tax recoverable in relation to donations received under Gift Aid or deeds of covenant is recognised at the time of the donation.

Income tax recoverable in relation to investment income is recognised at the time the investment income is receivable.

**2.4 Expenditure**

Expenditure is recognised once there is a legal or constructive obligation to transfer economic benefit to a third party, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is classified by activity. The costs of each activity are made up of the total of direct costs and shared costs, including support costs involved in undertaking each activity. Direct costs attributable to a single activity are allocated directly to that activity. Shared costs which contribute to more than one activity and support costs which are not attributable to a single activity are apportioned between those activities on a basis consistent with the use of resources. Central staff costs are allocated on the basis of time spent, and depreciation charges allocated on the portion of the asset's use.

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

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

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**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 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.

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**4. Income from donations and legacies**

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

**5. Income from other trading activities**

**Income from fundraising events**

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

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**5. Income from other trading activities (continued)**

**Income from non charitable trading activities**

	<b>Restricted funds 2021 £</b>	<b>Unrestricted funds 2021 £</b>	<b>Total funds 2021 £</b>	<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
<b>Total 2021</b>	<b>68</b>	<b>1,217</b>	<b>1,285</b>	<b>10,393</b>
<i>Total 2020</i>	<i>4,957</i>	<i>5,436</i>	<i>10,393</i>	

**6. Investment income**

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

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**7. Other incoming resources**

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

**8. Expenditure on raising funds**

**Costs of raising voluntary income**

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

**9. Analysis of grants**

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

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**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**

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

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**10. Analysis of expenditure by activities (continued)**

**Analysis of direct costs**

	<b>Total funds 2021 £</b>	<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
	<b>94,030</b>	<i>115,504</i>

**Analysis of support costs**

	<b>Total funds 2021 £</b>	<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
	<b>43,146</b>	<i>96,528</i>

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**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**

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

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

	<b>2021</b>	<i>2020</i>
	<b>No.</b>	<b>No.</b>
	<b>1</b>	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).

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**14. Intangible assets**

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



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**15. Tangible fixed assets**

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

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**16. Debtors**

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

**17. Creditors: Amounts falling due within one year**

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

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**18. Statement of funds**

**Statement of funds - current year**

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

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**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>
<b>Unrestricted funds</b>					
General Funds - all funds	39,726	68,043	(92,999)	1,778	16,548
<b>Restricted funds</b>					
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
	<u>99,890</u>	<u>137,759</u>	<u>(124,135)</u>	<u>(1,778)</u>	<u>111,736</u>
<b>Total of funds</b>	<u><u>139,616</u></u>	<u><u>137,759</u></u>	<u><u>(217,134)</u></u>	<u><u>-</u></u>	<u><u>128,284</u></u>

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

**Summary of funds - current year**

	<b>Balance at 1 April 2020 £</b>	<b>Income £</b>	<b>Expenditure £</b>	<b>Balance at 31 March 2021 £</b>
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>

**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
	<u>139,616</u>	<u>205,802</u>	<u>(217,134)</u>	<u>-</u>	<u>128,284</u>

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**19. Summary of funds (continued)**

**Restricted Funds**

**Type 2 Pompe's**

Supporting GSD Type 2, Pompe.

**Type 5 McArdles**

Supporting GSD Type 5, McArdle.

**Type 3 Cori**

Supporting GSD Type 3, Cori.

**Type 1 Von Gierke**

Supporting GSD Type 1, Von Gierke.

**Type 6 Hers Fund**

Supporting GSD Type 6, Hers.

**Hardship Fund**

Supporting patients and families suffering hardship.

**Conferences**

Supporting AGSD-UK Annual conference.

**Medical Advisory Board**

Supporting meetings of AGSD-UK Medical Advisors.

**Specialist Care Advisor**

Supporting the provision of a Pompe patient support worker.

**Type 0**

Supporting GSD Type 0.

**Patient Education and Empowerment**

Supporting patients and families by providing family days.

**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**

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

**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)
<b>Total</b>	<u>111,736</u>	<u>16,548</u>	<u>128,284</u>

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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 £	2020 £
<b>Land and buildings</b>		
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.