

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

**UNAUDITED**

**TRUSTEES' REPORT AND FINANCIAL STATEMENTS**

**FOR THE YEAR ENDED 31 MARCH 2018**



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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 2018**

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**Trustees**

Jayesh Pindolia  
Michael Porter, Chairman  
Stuart Alderson  
Nicholas Jones  
Ailsa Arthur (appointed 29 October 2017)  
Jane Mary Guy (appointed 29 October 2017)  
Heneage Legge-Bourke (appointed 26 November 2017)  
Phillip Prosser (appointed 28 October 2017, resigned 29 January 2018)  
Robert Seaborne (appointed 9 June 2018)

**Company registered number**

06981121

**Charity registered number**

1132271

**Registered office**

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

**Key management team**

Allan Muir, Charity Director

**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 2018**

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The Trustees present their annual report together with the financial statements of for the 1 April 2017 to 31 March 2018. The Trustees confirm that the Annual Report and financial statements of the company comply with the current statutory requirements, the requirements of the 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 (FRS 102) (effective 1 January 2015) as amended by Update Bulletin 1 (effective 1 January 2015).

Since the company qualifies as small under section 383, the strategic report required of medium and large companies under The Companies Act 2006 (Strategic Report and Director's Report) Regulations 2013 is not required.

**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 FOR ACHIEVING 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.

**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.

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**ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED**  
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**TRUSTEES' REPORT (continued)**  
**FOR THE YEAR ENDED 31 MARCH 2018**

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**Achievements and performance**

**a. REVIEW OF ACTIVITIES**

It has been another busy and rewarding year for the trustees, staff and volunteers. As always the financial environment for all UK charities particularly those smaller less well known charities like AGSD-UK, remains challenging. Despite this we have continued to deliver sustainable year-on-year financial improvements helping us to deliver services to our beneficiaries. During the year the trustee board met three times and in addition a number of trustee board sub committees met throughout the year. Two new trustees were appointed at the AGM and one further trustee was co-opted. There was one resignation from the trustee board.

In addition to income generation the major areas of focus for the year have been: further strengthening our policies and procedures, working with a professional systems company to update our IT infrastructure, developing a new website, succession planning for key roles, increasing our publication library and broadening our outreach services through the work of our Specialist Care Advisor.

In line with good governance and in anticipation of the new GDPR regulations, many governing documents and policies have been updated or created. In addition, the charity databases have been consolidated and a data-cleaning process commenced to ensure that we are only holding the personal data of our members and supporters that we require to work on their behalf. The trustees are aware of the need to ensure that we have appropriate policies and governance in place to protect individuals which is always a larger burden on smaller charities, but we are committed to ensuring that our practices and procedures are commensurate with the values of AGSD-UK, are robust enough to allow early identification and treatment of potential issues and provide appropriate assurance to our members, funders and donors.

The AGSD-UK annual conference was held at the impressive East Midlands Conference Centre, Nottingham. We were very fortunate to have international speakers discussing advances in metabolic medicine, research and neuromuscular insights. We held specialist workshops in Diet and Nutrition, Physiotherapy, care-giver support, and social care and benefits. Delegate fees were increased in 2017 by making a small reduction in the subsidy we give to our members. Delegate numbers did not suffer and the event continued to attract an impressive number of patients and families. The overall impression of the conference was that it fulfilled our objectives and the needs of the delegates and feedback was positive.

During the year meetings were held with the GSD volunteer Coordinators where they exchanged ideas for each of the GSD groups. The new website and conference planning were discussed in depth along with patient care and patient registries, walking courses, and fundraising for AGSD-UK.

As well as hosting our annual conference and a number of regional meetings, the charity was represented at three international conferences: World Symposium in San Diego, IGSD2017 in Groningen, and AGSD-US in Chicago. Two staff members and five volunteers from AGSD-UK joined an International conference in Groningen, The Netherlands. IGSD2017 was a joint scientific and patient meeting designed to bring patient groups and medical professionals together from around the world and two of our own volunteers chaired sessions and gave presentations at the conference. As more therapeutic options are reaching clinical trials, it is vitally important that AGSD-UK follows the global developments and understands the technologies involved. Attendance at events such as these adds to our store of knowledge about emerging developments in the field of glycogen storage diseases as well as supporting the 'vision' of AGSD-UK in being the primary and central focus for information and support, driving positive change for all people affected by Glycogen Storage Disease.

The AGSD-UK, through our McArdle Coordinator, is a founder members and key subject matter expert for the International Association for Muscle GSDs – IAMGSD, formally launched in 2017. The charity extends its influence and gains great benefit from national and international collaborations. We are members of the UK LSD Collaborative; a group of seven Patient Groups supporting Lysosomal Storage Disorders and join meetings with senior clinicians and NHS commissioners. We are also members of the Genetic Alliance and the European rare disease organisation (EURORDIS).

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**ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED**  
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**TRUSTEES' REPORT (continued)**  
**FOR THE YEAR ENDED 31 MARCH 2018**

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After a very successful year for our Specialist Care Advisor (SCA), funding was assured to allow for the full-time position to advance into its third year. The SCA continues to gain valuable experience and record important information about the patient community; we are still hopeful of growing the team of care advisors, and we are constantly seeking alternative sources of income to support that objective.

The SCA has had a successful year raising grants for families or individuals requiring modifications to their homes or transport. She is also developing disease-specific days and family days, in collaboration with the NHS specialist centres.

The SCA has made positive impact to families and individuals in many areas, including:

- Network building with industry partners, medical centres and charities.
- Patients with historic diagnoses located through social media; and many have now joined AGSD UK.
- Provided phone support, materials and needs assessment.
- Supporting diagnostic pathway – links established and maintained with MyAware CEO.
- Working with Muscular Dystrophy UK to finalise a Pompe factsheet.
- Working with NHS dieticians to develop a leaflet giving nutritional advice.
- A much requested session for care-givers was delivered at conference 2017, tips were shared, and a Facebook group initiated.
- Supporting patients through the diagnostic process with advice/counselling/letter writing
- Providing social benefits support explaining processes, writing support letters, obtaining medical support letters, completing forms and help with assessments. Applicants find this extremely challenging and depressing. All submissions successful, with no appeals needed.
- Claims for ESA, PIP, DLA submitted.
- Providing advocacy regarding orthotics, housing, parental work absence, school absence, disabled parking bay application, school transport, social care assessment, transfer to personal health budget, fundraising.
- Member in Wales supported through lengthy process towards securing ERT, including letter writing, moral support and referral to useful sources. ERT treatment successfully confirmed and now started.
- Working closely with Pompe support team of volunteers to support their development of publications.

We have published a number books and booklets during the year. "Pompedoo" is a recent book for children and families living with Pompe disease. It is an adaptation of a charming children's storybook for Spinal Muscular Atrophy (SMA). The Pompe support team published a Medical Alert Card for members and a Medical Overview of Pompe Disease was published and sent free of charge to all members with that condition. The booklet empowers patients to explain their condition, medical and social needs to healthcare professionals.

International Pompe Day was again celebrated in April. The Pompe support team arranged a social event at the Hilton, Coventry. It was well attended and very much appreciated by those present. The event provides an opportunity for Pompe adults to learn more about the AGSD-UK and exchange personal experiences in an informal and comfortable environment.

Our collaboration with the Royal College of General Practitioners (RCGP) to build an eLearning module for GPs, hosted by the RCGP was successfully completed and launched in April 2018. Over the coming 12 months we hope to understand how the module is helping reduce the time to diagnosis for GSD patients and their families.

The McArdle walking courses were again well attended. The week-long events take place in Wales and are organised by our McArdle coordinator. They are designed to show those with McArdle disease how to exercise effectively and safely and help patients achieve far more than they had previously thought possible.

Individual fundraising events from the GSD community were again very impressive. We were very proud of one member with McArdle disease who took part in the London Marathon, finishing in just over 7 hours and raising impressive funds for AGSD-UK. Her story was published on the "BBC: Get inspired" website and she was

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**TRUSTEES' REPORT (continued)**  
**FOR THE YEAR ENDED 31 MARCH 2018**

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interviewed for BBC Wales radio on 21st April. AGSD-UK acknowledged her achievement during the October conference. We continued to recruit participants into other national events such as the London Vitality 10k run, the Prudential Ride London-Surrey 100 mile cycling event, and smaller fun runs around the country.

From a research perspective, Allan Muir our Charity Director, has been asked to join a multi disciplinary panel of world leading experts in drug development for neuromuscular disease. He will sit on a panel to consider and respond to applications for advice from investigators, both industry and academic, on their therapy development. The first of these applications will be for gene therapy development for Pompe disease.

As a small charity supporting a number of ultra rare conditions we will always be a long way down the queue in terms of people's awareness of who we are and what we do. However, we have a track record of punching well above our weight and we will continue to strive to beat the drum for the glycogen storage disease community in the UK.

As always the charity is extremely grateful for the continuing support of our donors, fund raisers, grant makers and various sponsors from pharmaceutical, nutrition, and biotechnology industries. Their efforts on our behalf enables the charity to maintain its support to all people affected by GSD in the UK.

**Financial review**

**a. GOING CONCERN**

The company has cash resources and has no requirement for external funding. At the date of signing the accounts the unrestricted reserve stands at £20,952. 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. 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.

**c. 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 £20,952 which is an increase from the previous year (£4,975). 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.

**Structure, governance and management**

**a. CONSTITUTION**

The company is registered as a charitable company limited by guarantee and was set up as 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".

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**ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED**  
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**TRUSTEES' REPORT (continued)**  
**FOR THE YEAR ENDED 31 MARCH 2018**

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**b. METHOD 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. REMUNERATION OF KEY MANAGEMENT PERSONNEL**

The company currently has two permanent members of staff – Charity Director and Specialist Care Advisor. The remuneration for both posts was benchmarked at or below market rate prior to appointment and is reviewed by Trustees annually.

**d. ORGANISATIONAL STRUCTURE AND DECISION MAKING**

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 are supported by the Development Director. They meet as a group three times a year for peer support and development in their role.

**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

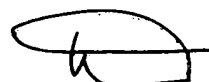
The Trustees are satisfied that systems, procedures and plans are in place to mitigate exposure to major risks.

**Plans for future periods**

**a. FUTURE DEVELOPMENTS**

The overall activity of the Association is guided by charitable objectives and the detail is provided in a Strategic Plan.

This report was approved by the Trustees, on 19/6/18 and signed on their behalf by:



**Michael Porter, Chairman**  
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 2018**

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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 2018.

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.

**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.

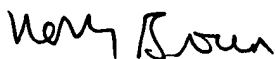
**INDEPENDENT EXAMINER'S STATEMENT**

I have completed my examination. I can 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.

Signed:



Dated: 3 September 2018

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 2018**

	Note	Restricted funds 2018 £	Unrestricted funds 2018 £	Total funds 2018 £	Total funds 2017 £
<b>INCOME FROM:</b>					
Donations and grants	2	200,512	48,804	249,316	272,964
Other trading activities	3,4	28,559	21,124	49,683	27,728
Investments	5	-	26	26	61
Other income	6	-	400	400	-
<b>TOTAL INCOME</b>		<b>229,071</b>	<b>70,354</b>	<b>299,425</b>	<b>300,753</b>
<b>EXPENDITURE ON:</b>					
Raising funds	7	-	3,064	3,064	7,454
Charitable activities	8,9,10	178,159	51,313	229,472	258,506
<b>TOTAL EXPENDITURE</b>		<b>178,159</b>	<b>54,377</b>	<b>232,536</b>	<b>265,960</b>
<b>NET INCOME BEFORE OTHER RECOGNISED GAINS AND LOSSES</b>		<b>50,912</b>	<b>15,977</b>	<b>66,889</b>	<b>34,793</b>
<b>NET MOVEMENT IN FUNDS</b>		<b>50,912</b>	<b>15,977</b>	<b>66,889</b>	<b>34,793</b>
<b>RECONCILIATION OF FUNDS:</b>					
Total funds brought forward		128,147	4,975	133,122	98,329
<b>TOTAL FUNDS CARRIED FORWARD</b>		<b>179,059</b>	<b>20,952</b>	<b>200,011</b>	<b>133,122</b>

The notes on pages 10 to 25 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 2018**

	Note	£	2018 £	£	2017 £	£
<b>FIXED ASSETS</b>						
Intangible assets	14		8,808		5,872	
Tangible assets	15		2,034		2,562	
			<u>10,842</u>		<u>8,434</u>	
<b>CURRENT ASSETS</b>						
Debtors	16	7,415		33,347		
Cash at bank and in hand		<u>186,284</u>		<u>102,229</u>		
		193,699		135,576		
<b>CREDITORS: amounts falling due within one year</b>	17	<u>(4,530)</u>		<u>(10,888)</u>		
<b>NET CURRENT ASSETS</b>			<u>189,169</u>		<u>124,688</u>	
<b>NET ASSETS</b>			<u>200,011</u>		<u>133,122</u>	
<b>CHARITY FUNDS</b>						
Restricted funds	19		179,059		128,147	
Unrestricted funds	19		20,952		4,975	
<b>TOTAL FUNDS</b>			<u>200,011</u>		<u>133,122</u>	

The company's financial statements have been prepared in accordance with the provisions applicable to companies subject to the small companies regime.

The Trustees consider that the company is entitled to exemption from the requirement to have an audit under the provisions of section 477 of the Companies Act 2006 ("the Act") and members have not required the company to obtain an audit for the year in question in accordance with section 476 of the Act.

The Trustees acknowledge their responsibilities for complying with the requirements of the Companies Act 2006 with respect to accounting records and the preparation of financial statements.

The financial statements were approved and authorised for issue by the Trustees on 19/8/2018 and signed on their behalf, by:

Michael Porter, Chairman

The notes on pages 10 to 25 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 2018**

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**1. ACCOUNTING POLICIES**

**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.

**1.2 Basis of preparation of financial statements**

The financial statements have been prepared in accordance with 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) - (Charities SORP (FRS 102)), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) and the Companies Act 2006.

The financial statements have been prepared to give a 'true and fair' view and have departed from the Charities (Accounts and Reports) Regulations 2008 only to the extent required to provide a 'true and fair' view. This departure has involved following the Charities SORP (FRS 102) published on 16 July 2014 rather than the Accounting and Reporting by Charities: Statement of Recommended Practice effective from 1 April 2005 which has since been withdrawn.

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.

**1.3 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.

**1.4 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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**NOTES TO THE FINANCIAL STATEMENTS**  
**FOR THE YEAR ENDED 31 MARCH 2018**

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**1. ACCOUNTING POLICIES (continued)**

**1.5 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.

**1.6 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.

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 on the company's educational operations, including support costs and costs relating to the governance of the company apportioned to charitable activities.

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.

**1.7 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.

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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 2018**

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**1. ACCOUNTING POLICIES (continued)**

**1.8 Intangible fixed 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 and are subsequently measured at cost net of amortisation and any provision for impairment

Amortisation is provided on intangible fixed assets at rates calculated to write off the cost of each asset, less their estimated residual value, over their expected useful lives on the following bases:

Website development	-	Over 5 years
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**1.9 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 carried at cost, net of depreciation and any provision for impairment. Depreciation is provided at rates calculated to write off the cost of fixed assets, less their estimated residual value, over their expected useful lives on the following bases:

Office equipment	-	25% Reducing balance
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**1.10 Pensions**

The pension costs charged 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.

**1.11 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.

**1.12 Role of Volunteers**

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

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**NOTES TO THE FINANCIAL STATEMENTS  
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**1. ACCOUNTING POLICIES (continued)**

**1.13 Significant accounting estimates and areas of judgement**

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) Donation 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 £72,310 (2017: £93,800). This is based on the open market value of the benefits received.

**2. INCOME FROM DONATIONS AND LEGACIES**

	<b>Restricted funds 2018 £</b>	<b>Unrestricted funds 2018 £</b>	<b>Total funds 2018 £</b>	<b>Total funds 2017 £</b>
Donations	1,771	13,594	15,365	12,454
Legacies	-	2,000	2,000	-
Grants	133,951	20,984	154,935	164,081
Donations in kind	64,790	7,520	72,310	93,800
Gift aid	-	4,706	4,706	2,629
<b>Total donations and legacies</b>	<b>200,512</b>	<b>48,804</b>	<b>249,316</b>	<b>272,964</b>
<b>Total 2017</b>	<b>213,764</b>	<b>59,200</b>	<b>272,964</b>	

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**3. ACTIVITIES TO GENERATE FUNDS**

	<b>Restricted funds 2018 £</b>	<b>Unrestricted funds 2018 £</b>	<b>Total funds 2018 £</b>	<b>Total funds 2017 £</b>
Fundraising events	3,821	20,144	23,965	13,434
	<u>3,821</u>	<u>20,144</u>	<u>23,965</u>	<u>13,434</u>
<i>Total 2017</i>	<u>810</u>	<u>12,624</u>	<u>13,434</u>	

**4. INCOMING RESOURCES FROM CHARITABLE ACTIVITIES**

	<b>Restricted funds 2018 £</b>	<b>Unrestricted funds 2018 £</b>	<b>Total funds 2018 £</b>	<b>Total funds 2017 £</b>
Conference	20,942	-	20,942	9,005
Subscriptions	-	980	980	695
Book sales	1,126	-	1,126	1,329
Walking courses	2,670	-	2,670	3,265
	<u>24,738</u>	<u>980</u>	<u>25,718</u>	<u>14,294</u>
Incoming resources from charitable activities	<u>24,738</u>	<u>980</u>	<u>25,718</u>	<u>14,294</u>

In 2017, of the total income from charitable activities, £902 was to unrestricted funds and £13,392 was to restricted funds.

**5. INVESTMENT INCOME**

	<b>Restricted funds 2018 £</b>	<b>Unrestricted funds 2018 £</b>	<b>Total funds 2018 £</b>	<b>Total funds 2017 £</b>
Investment income	-	26	26	61
	<u>-</u>	<u>26</u>	<u>26</u>	<u>61</u>
<i>Total 2017</i>	<u>-</u>	<u>61</u>	<u>61</u>	



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**6. OTHER INCOMING RESOURCES**

	<b>Restricted funds 2018 £</b>	<b>Unrestricted funds 2018 £</b>	<b>Total funds 2018 £</b>	<b>Total funds 2017 £</b>
Other income	-	400	400	-
<i>Total 2017</i>	-	-	-	

**7. FUNDRAISING TRADING**

	<b>Restricted funds 2018 £</b>	<b>Unrestricted funds 2018 £</b>	<b>Total funds 2018 £</b>	<b>Total funds 2017 £</b>
Fundraising expenses	-	3,064	3,064	7,454
<i>Total 2017</i>	-	7,454	7,454	

**8. DIRECT COSTS**

	<b>Charitable activities £</b>	<b>Total 2018 £</b>	<b>Total 2017 £</b>
Conference	62,740	62,740	54,559
Euromac	-	-	6,396
Walking courses	4,134	4,134	2,951
Consultancy	39,500	39,500	39,500
Travel and accommodation expenses	12,293	12,293	13,227
Wages and salaries	28,055	28,055	21,000
National insurance	2,746	2,746	1,820
Pension cost	281	281	210
	<b>149,749</b>	<b>149,749</b>	<b>139,663</b>
<i>Total 2017</i>	<b>139,663</b>	<b>139,663</b>	

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**9. ANALYSIS OF GRANTS**

	Grants 2018 £	Total 2018 £	Total 2017 £
Grants	3,782	3,782	22,263

In 2018 no grants were made to institutions (2017: 2) and 6 to individuals (2017: 7).

Grants to institutions were as follows:

	2018 £	2017 £
Brunel University	-	1,000
Royal College of General Practitioners	-	18,205
Total	-	19,205

**10. SUPPORT COSTS**

	Charitable activities £	Total 2018 £	Total 2017 £
Rent	4,200	4,200	4,200
Office costs	2,698	2,698	3,714
Online services	1,586	1,586	1,075
Website and computer costs	10,039	10,039	39,728
Sundry expenses	2,736	2,736	519
Insurance	559	559	436
Printing, postage and stationery	12,247	12,247	8,156
Depreciation - office equipment	678	678	854
Consultancy	1,295	1,295	-
Accountancy & payroll	3,558	3,558	1,591
Independent examiners fee	2,235	2,235	2,190
Wages and salaries	33,600	33,600	33,600
National insurance	510	510	517
	75,941	75,941	96,580
Total 2017	95,580	95,580	

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**10. SUPPORT COSTS (continued)**

During the year ended 31 March 2018, the company incurred the following Governance costs:  
£7,088 (2017 - £3,781) included within the table above.

**11. NET INCOME/(EXPENDITURE)**

This is stated after charging:

	2018 £	2017 £
Depreciation of tangible fixed assets:		
- owned by the charity	678	854

Trustees received remuneration amounting to £NIL in the current year (2017 - £NIL).  
During the year, no Trustees received any benefits in kind (2017 - £NIL).  
During the year, 3 Trustees received reimbursement of expenses of £526 (2017 - £NIL) for travel and accommodation.

**12. INDEPENDENT EXAMINER'S REMUNERATION**

The Independent Examiner's remuneration amounts to an Independent Examination fee of £2,235 (2017 - £2,190).

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**13. STAFF COSTS**

Staff costs were as follows:

	2018 £	2017 £
Wages and salaries	61,655	54,600
Social security costs	3,256	2,337
Pension costs	281	210
	<u>65,192</u>	<u>57,147</u>

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

2018 No.	2017 No.
2	2

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

The key management personnel of the charity are the Trustees and Development Director. Total employee benefits of key management personnel of the charity were £34,110 (2017: £34,117).

**14. INTANGIBLE FIXED ASSETS**

	Website development £
<b>Cost</b>	
At 1 April 2017	5,872
Additions	2,936
At 31 March 2018	<u>8,808</u>
<b>Carrying amount</b>	
At 31 March 2018	<u>8,808</u>
At 31 March 2017	<u>5,872</u>

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**15. TANGIBLE FIXED ASSETS**

	Office equipment £
<b>Cost</b>	
At 1 April 2017	5,724
Additions	150
At 31 March 2018	<u>5,874</u>
<b>Depreciation</b>	
At 1 April 2017	3,162
Charge for the year	678
At 31 March 2018	<u>3,840</u>
<b>Net book value</b>	
At 31 March 2018	<u>2,034</u>
At 31 March 2017	<u>2,562</u>

**16. DEBTORS**

	2018 £	2017 £
Trade debtors	-	160
Prepayments and accrued income	7,415	33,187
	<u>7,415</u>	<u>33,347</u>

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

	2018 £	2017 £
Other taxation and social security	545	18
Other creditors	1,519	5,714
Accruals and deferred income	2,466	5,156
	<u>4,530</u>	<u>10,888</u>

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**NOTES TO THE FINANCIAL STATEMENTS**  
**FOR THE YEAR ENDED 31 MARCH 2018**

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**18. FINANCIAL INSTRUMENTS**

	<b>2018</b>	<b>2017</b>
	<b>£</b>	<b>£</b>
Financial assets measured at amortised cost	<b>186,284</b>	<b>120,197</b>
Financial liabilities measured at amortised cost	<b>4,530</b>	<b>10,870</b>

Financial assets measured at amortised cost comprise cash at bank, trade debtors and accrued income.

Financial liabilities measured at amortised cost comprise PAYE, accruals and other creditors

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**NOTES TO THE FINANCIAL STATEMENTS  
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**19. STATEMENT OF FUNDS**

**STATEMENT OF FUNDS - CURRENT YEAR**

	Balance at 1 April 2017 £	Income £	Expenditure £	Balance at 31 March 2018 £
<b>Unrestricted funds</b>				
General Funds - all funds	4,975	70,354	(54,377)	20,952
<b>Restricted funds</b>				
Type 2 Pompe's	15,912	4,298	(5,509)	14,701
Type 5 McArdles	17,811	43,543	(44,926)	16,428
Type 3 Cori	7,010	198	(166)	7,042
Type 1 Von Gierke	6,147	3,849	-	9,996
Awards for All	22	-	-	22
Type 6 Hers Fund	602	-	-	602
Hardship fund	3,434	1,300	(2,708)	2,026
Conferences	77	103,322	(79,488)	23,911
Medical Advisory Board	2,065	-	-	2,065
Specialist Care Advisor	47,875	57,238	(44,965)	60,148
Type 0	165	-	-	165
Website Redevelopment Fund	24,905	-	-	24,905
Patient Education and Empowerment	2,122	15,323	(397)	17,048
	128,147	229,071	(178,159)	179,059
<b>Total of funds</b>	<b>133,122</b>	<b>299,425</b>	<b>(232,536)</b>	<b>200,011</b>

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**19. STATEMENT OF FUNDS (continued)**

**STATEMENT OF FUNDS - PRIOR YEAR**

	<i>Balance at 1 April 2016 £</i>	<i>Income £</i>	<i>Expenditure £</i>	<i>Transfers in/out £</i>	<i>Balance at 31 March 2017 £</i>
<b>Unrestricted funds</b>					
General Funds - all funds	12,766	72,787	(81,303)	725	4,975
	<u>12,766</u>	<u>72,787</u>	<u>(81,303)</u>	<u>725</u>	<u>4,975</u>
<b>Restricted funds</b>					
Type 2 Pompe's	17,325	25,362	(26,775)	-	15,912
Type 5 McArdles	18,064	44,005	(45,346)	1,088	17,811
Type 3 Cori	7,553	89	(632)	-	7,010
Type 1 Von Gierke	4,809	1,465	(127)	-	6,147
Euromac	-	12,946	(11,133)	(1,813)	-
Awards for All	22	-	-	-	22
Type 6 Hers Fund	602	-	-	-	602
Hardship fund	3,542	1,500	(1,608)	-	3,434
Conferences	14	63,029	(62,966)	-	77
Medical Advisory Board	65	2,000	-	-	2,065
Specialist Care Advisor	33,567	50,000	(35,692)	-	47,875
Type 0	-	165	-	-	165
Website Redevelopment Fund	-	24,905	-	-	24,905
Patient Education and Empowerment	-	2,500	(378)	-	2,122
	<u>85,563</u>	<u>227,966</u>	<u>(184,657)</u>	<u>(725)</u>	<u>128,147</u>
Total of funds	<u>98,329</u>	<u>300,753</u>	<u>(265,960)</u>	<u>-</u>	<u>133,122</u>

**SUMMARY OF FUNDS - CURRENT YEAR**

	<i>Balance at 1 April 2017 £</i>	<i>Income £</i>	<i>Expenditure £</i>	<i>Balance at 31 March 2018 £</i>
General funds	4,975	70,354	(54,377)	20,952
Restricted funds	128,147	229,071	(178,159)	179,059
	<u>133,122</u>	<u>299,425</u>	<u>(232,536)</u>	<u>200,011</u>



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**NOTES TO THE FINANCIAL STATEMENTS  
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**19. STATEMENT OF FUNDS (continued)**

**SUMMARY OF FUNDS - PRIOR YEAR**

	<i>Balance at 1 April 2016</i>	<i>Income</i>	<i>Expenditure</i>	<i>Balance at 31 March 2017</i>
	£	£	£	£
General funds	12,766	72,787	(81,303)	4,975
Restricted funds	85,563	227,966	(184,657)	128,147
	<u>98,329</u>	<u>300,753</u>	<u>(265,960)</u>	<u>133,122</u>

**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.

**Awards for All**

The Big Lottery - production of literature on all GSD's.

**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.

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**NOTES TO THE FINANCIAL STATEMENTS  
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**19. STATEMENT OF FUNDS (continued)**

**Specialist Care Advisor**

Supporting the provision of a Pompe patient support worker.

**Type 0**

Supporting GSD Type 0.

**Website Redevelopment Fund**

Supporting the redevelopment of the charity's website

**Patient Education and Empowerment**

Supporting patients and families by providing family days.

**20. ANALYSIS OF NET ASSETS BETWEEN FUNDS**

**ANALYSIS OF NET ASSETS BETWEEN FUNDS - CURRENT YEAR**

	Restricted funds 2018 £	Unrestricted funds 2018 £	Total funds 2018 £
Intangible fixed assets	8,808	-	8,808
Tangible fixed assets	-	2,034	2,034
Current assets	171,470	22,229	193,699
Creditors due within one year	(1,219)	(3,311)	(4,530)
	<u>179,059</u>	<u>20,952</u>	<u>200,011</u>

**ANALYSIS OF NET ASSETS BETWEEN FUNDS - PRIOR YEAR**

	Restricted funds 2017 £	Unrestricted funds 2017 £	Total funds 2017 £
Intangible fixed assets	5,872	-	5,872
Tangible fixed assets	-	2,562	2,562
Current assets	122,275	13,301	135,576
Creditors due within one year	-	(10,888)	(10,888)
	<u>128,147</u>	<u>4,975</u>	<u>133,122</u>

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**NOTES TO THE FINANCIAL STATEMENTS**  
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**21. PENSION COMMITMENTS**

The Charity operates a defined contribution pension scheme. The assets of the scheme are held separately from those of the Charity in independently administered funds. The pension cost shown in note 13 represent the contributions payable by the Charity to these funds.

**22. OPERATING LEASE COMMITMENTS**

At 31 March 2018 the total of the Charity's future minimum lease payments under non-cancellable operating leases was:

	<b>Land and buildings</b>	
	<b>2018</b>	<b>2017</b>
	<b>£</b>	<b>£</b>
<b>Amounts payable:</b>		
Within 1 year	<b>4,200</b>	<b>4,200</b>

**23. RELATED PARTY TRANSACTIONS**

There were no related party transactions for the year ended 31 March 2018.