

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 2017

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

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ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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**REFERENCE AND ADMINISTRATIVE DETAILS OF THE COMPANY, ITS TRUSTEES AND ADVISERS
FOR THE YEAR ENDED 31 MARCH 2017**

Trustees

Jayesh Pindolia
Michael Porter, Chairman
Shaun Griffin (resigned 21 January 2017)
Stuart Alderson
Nicholas Jones (appointed 21 January 2017)

Company registered number

06981121

Charity registered number

1132271

Registered office

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

Independent examiner

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

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

TRUSTEES' REPORT
FOR THE YEAR ENDED 31 MARCH 2017

The Trustees present their annual report together with the financial statements of for the 1 April 2016 to 31 March 2017. 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.

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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TRUSTEES' REPORT (continued)
FOR THE YEAR ENDED 31 MARCH 2017

Achievements and performance

a. REVIEW OF ACTIVITIES

The trustees are happy to report on another busy and rewarding year for the charity. There was one resignation from the trustee board and one new appointment and this was bolstered by two additional trustees being co-opted following the 2016 Annual General Meeting.

In order to manage costs staffing levels remained low with two permanent members of staff on the payroll. They are expertly supported by a large number of volunteers, many with specialist skills and experience. This model contributes to our service delivery professionalism and is part of our social capital. Trustees include four people who ran/run large companies and they bring a businesslike approach to everything we do and they are very active on a daily basis. We have thirteen volunteers, all of whom have a GSD themselves or support a family member. They provide a specific point of contact for members, navigate services, offer peer support, network, contribute to our annual conference, draft publications and attend meetings where relevant. We have a volunteer operating as a charity development consultant and funding advisor who helped found the Institute of Money Advisors and Gingerbread. She has redeveloped three Citizens Advice Bureaus enabling them to grow in sustainable ways. For AGSD-UK she has been focused on supporting governance practices and internal policy auditing and continues to be heavily involved in enhanced governance and policy implementation. Outside of his paid role our Charity Director provides voluntary effort for international GSD work and we have a volunteer McArdles co-ordinator who works full time with specialist centres, drafts material, runs courses and is internationally recognised as a McArdles expert. The social capital received from specialist volunteers have for the first time been recognised and conservatively valued in our annual accounts.

In addition to income maximisation and cost controls the trustees have been focused on the development and implementation of a comprehensive set of policies and procedures, the design and development of a new website, the implementation of a professionally managed secure IT infrastructure and the creation of two trustee sub committees – organisational development and fund raising. The aim of the bulk of this work is threefold; to ensure legal and regulatory compliance, to support submissions for funding to larger charitable foundations and trusts and to position the organisation for future growth.

Increased funding was secured to retain our Specialist Care Advisor (SCA) to April 2018 and to increase employment to a full-time position. The SCA provides considerable non-medical support to families and individuals and has made a measurable difference to the quality of life of those she has helped. Her influence is felt particularly the adult and paediatric Pompe communities but also across other areas of the charity's work. Based on the success of this position, the charity is actively seeking to raise additional funds to enable the recruitment of further SCAs to cover the whole GSD community, focusing initially on GSD families with young children.

In October the annual conference was held at Tortworth Court Hotel, Gloucestershire. This was a commemoration of 30 years since the AGSD-UK was founded and was extremely well attended by 170 delegates. The event received significant sponsorship from our corporate partners and was again designed with fewer scientific presentations in order to provide more opportunities for discussion and delegate interaction. Feedback on the conference was very positive.

During the year meetings were held with the GSD volunteer Coordinators for them to exchange ideas and to learn from each other. Specific topics for discussion included: help for planning fundraising events, designing and development of the new website, new publications and the annual conference. NHS professionals were invited to these meetings to support the design of publications for hepatic GSD's.

We have published a number books and booklets during the year. "GSD and Me" is an educational storybook for children with GSD 1. Other GSDs have found the book informative and interesting and there is a suggestion to create a version for GSD IX. There was no specific funding for this project therefore the minimal print costs were attributed to the GSD I (Von Gierke) Fund.

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TRUSTEES' REPORT (continued)
FOR THE YEAR ENDED 31 MARCH 2017

The McArdle Coordinator continues to extend the range of booklets; the latest is titled "At Work with McArdle Disease" and is aimed at helping employers and colleagues to understand the disease and make the necessary adjustments for people with this condition. The McArdle group, led by our coordinator are extremely active; they are currently researching the substantial benefits from a ketogenic diet to alleviate some of their symptoms.

As reported last year the Pompe Support Team, another volunteer group, received a grant from Amicus Therapeutics to develop a book full of advice for late-onset Pompe disease, "101 Tips for an easier life with Pompe Disease". The book has now been published and a free copy sent to every patient in the UK. The book has been very well received and internet sales have been encouraging.

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.

The AGSD-UK successfully applied for one of the coveted 2017 Sanofi-Genzyme Patient Advocacy Leadership (PAL) Awards; the awards will finance a collaborative project with the Royal College of General Practitioners (RCGP) to build an eLearning module for GPs. The intention is to raise awareness of glycogen storage disease within primary healthcare so that fewer patients are subjected to unacceptably lengthy diagnostic journeys. Some GSDs can take over 10 years to receive a confirmed diagnosis.

The McArdle Advisory Panel continued to meet with the NHS Highly Specialised Service for McArdle Disease at the National Hospital for Neurology and Neurosurgery.

The McArdle walking courses were again well attended. These are run in Wales by our GSD coordinator and 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. For the first time a course was also run for children with the condition, and their parents. Feedback from the courses was excellent with one parent stating "it has completely changed their son's outlook on life". The walking courses are all endorsed by the medical team at the McArdle clinic in London.

AGSD-UK continued to provide a patient group input to the Euromac Registry consortium by undertaking the "Dissemination" work package. This work was completed this year and no further funding is expected once the final payment is received.

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. We are also members of the Genetic Alliance and the European rare disease organisation (EURORDIS) held a conference in Edinburgh during May 2016 where details of the Metabolic European Reference Networks (MetabERN) were discussed. Our Charity Director is Vice-Chair of the International Pompe Association and our McArdle Coordinator is a founder member of the International Association of Muscle GSDs (IamGSD).

Community fundraising was again important and we raised significant funds through sponsored walks, running and cycling events, cake sales etc, although we would like to increase this important strand of our income.

The SCA has been very successful at 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:

- Highly successful support of Personal Independence Payment (PIP) applications and appeals.
- Referrals to social services Occupational Therapist or social worker.
- Letters of support written for DFG (Disabled Facilities Grant).
- Enabling newly diagnosed to start treatment by referring to medical centre.

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TRUSTEES' REPORT (continued)
FOR THE YEAR ENDED 31 MARCH 2017

- Compiled school Education Health Care Plans & attending multi-disciplinary meetings.
- More patient referrals to AGSD-UK are being received from NHS specialist centres.
- Regional patient meetings and family days organised
- Siblings of people with Pompe identified and successfully referred for positive testing.
- Ongoing emotional support and signposting for newly diagnosed people.
- Articles for newsletter.

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 £4,975. 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 £4,975 which is a decrease from the previous year (£12,766). 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 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. 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.

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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TRUSTEES' REPORT (continued)
FOR THE YEAR ENDED 31 MARCH 2017

c. REMUNERATION OF KEY MANAGEMENT PERSONNEL

The company currently has two part time 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 Development 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 18 December 2017 and signed on their behalf by:

Michael Porter, Chairman
Trustee

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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INDEPENDENT EXAMINER'S REPORT
FOR THE YEAR ENDED 31 MARCH 2017

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED

I report on the financial statements of the company for the year ended 31 March 2017 which are set out on pages 9 to 25.

This report is made solely to the company's Trustees, as a body, in accordance with section 145 of the Charities Act 2011 and regulations made under section 154 of that Act. 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.

The financial statements have been prepared in accordance with Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standards applicable in the UK and Republic of Ireland (FRS 102) in preference to the Accounting and Reporting by Charities: Statement of Recommended Practice issued on 1 April 2005 which is referred to in the extant regulations but has been withdrawn.

This has been done in order for the accounts to provide a true and fair view in accordance with the Generally Accepted Accounting Practice effective for reporting periods beginning on the after 1 January 2015.

RESPECTIVE RESPONSIBILITIES OF TRUSTEES AND EXAMINER

The Trustees, who are also the directors of the company for the purposes of company law, are responsible for the preparation of the financial statements. The Trustees consider that an audit is not required for this year under section 144(2) of the Charities Act 2011 (the Act) and that an independent examination is needed.

Having satisfied myself that the company is not subject to audit under charity or company law and is eligible for independent examination, it is my responsibility to:

- examine the financial statements under section 145 of the Act;
- follow the procedures laid down in the general Directions given by the Charity Commission under section 145(5)(b) of the Act; and
- state whether particular matters have come to my attention.

BASIS OF INDEPENDENT EXAMINER'S REPORT

My examination was carried out in accordance with the general Directions given by the Charity Commission. An examination includes a review of the accounting records kept by the company and a comparison of the financial statements presented with those records. It also includes consideration of any unusual items or disclosures in the financial statements, and seeking explanations from you as Trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit, and consequently no opinion is given as to whether the financial statements present a 'true and fair view' and the report is limited to those matters set out in the statement below.

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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INDEPENDENT EXAMINER'S REPORT (continued)
FOR THE YEAR ENDED 31 MARCH 2017

INDEPENDENT EXAMINER'S STATEMENT

In connection with my examination, no matter has come to my attention:

- (1) which gives me reasonable cause to believe that in any material respect the requirements:
- to keep accounting records in accordance with section 386 of the Companies Act 2006; and
 - to prepare financial statements which accord with the accounting records, Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard in the UK and Republic of Ireland (FRS 102) and in other respects comply with the accounting requirements of section 396 of the Companies Act 2006 and with the methods and principles of the Statement of Recommended Practice: Accounting and Reporting by Charities.
- have not been met; or
- (2) to which, in my opinion, attention should be drawn in order to enable a proper understanding of the financial statements to be reached.

Signed:

Dated: 21 December 2017

Helen Drew FCA

Crowe Clark Whitehill LLP
Black Country House
Rounds Green Road
Oldbury
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 2017**

	Note	Restricted funds 2017 £	Unrestricted funds 2017 £	Total funds 2017 £	Total funds 2016 £
INCOME FROM:					
Donations and grants	2	213,764	59,200	272,964	77,576
Other trading activities	3,4	14,202	13,526	27,728	59,483
Investments	5	-	61	61	120
TOTAL INCOME		227,966	72,787	300,753	137,179
EXPENDITURE ON:					
Raising funds	6	-	7,454	7,454	9,416
Charitable activities	7,8,9	184,657	73,849	258,506	107,193
TOTAL EXPENDITURE		184,657	81,303	265,960	116,609
NET INCOME / (EXPENDITURE) BEFORE TRANSFERS					
Transfers between Funds	18	43,309 (725)	(8,516) 725	34,793 -	20,570 -
NET INCOME / (EXPENDITURE) BEFORE OTHER RECOGNISED GAINS AND LOSSES					
		42,584	(7,791)	34,793	20,570
NET MOVEMENT IN FUNDS		42,584	(7,791)	34,793	20,570
RECONCILIATION OF FUNDS:					
Total funds brought forward		85,563	12,766	98,329	77,759
TOTAL FUNDS CARRIED FORWARD		128,147	4,975	133,122	98,329

The notes on pages 11 to 25 form part of these financial statements.

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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REGISTERED NUMBER: 06981121

BALANCE SHEET
AS AT 31 MARCH 2017

	Note	2017		2016	
		£	£	£	£
FIXED ASSETS					
Intangible assets	13		5,872		-
Tangible assets	14		2,562		721
			8,434		721
CURRENT ASSETS					
Debtors	15	33,347		16,701	
Cash at bank and in hand		102,229		88,338	
		135,576		105,039	
CREDITORS: amounts falling due within one year	16	(10,888)		(7,431)	
NET CURRENT ASSETS			124,688		97,608
NET ASSETS			133,122		98,329
CHARITY FUNDS					
Restricted funds	18		128,147		85,563
Unrestricted funds	18		4,975		12,766
TOTAL FUNDS			133,122		98,329

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 18 December 2017 and signed on their behalf, by:

Michael Porter, Chairman

The notes on pages 11 to 25 form part of these financial statements.

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2017

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.

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2017

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 and include project management carried out at Headquarters. Governance costs are those incurred in connection with administration of the company and compliance with constitutional and statutory requirements.

Costs of generating voluntary income 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 academy trust's educational operations, including support costs and costs relating to the governance of the academy trust 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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NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2017

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 at the following rates:

Website development - Over 5 years

1.9 Tangible fixed assets and depreciation

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

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.

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2017**

1. ACCOUNTING POLICIES (continued)

1.13 Significant accounting estimates and areas of judgement

Preparation of the financial statements may require management to make significant judgments and estimates. The charity makes estimates and assumptions concerning the future. The resulting accounting estimates and assumptions will, by definition, seldom equal the related actual results.

Critical areas of judgement:

- (i) Donation of consulting by Andrew Wakelin
- (ii) Donations of conference guest speakers
- (iii) Donation of services including printing and meeting rooms
- (iv) Donation of IT security and consultancy work

In accordance with the Charities SORP FRS 102, the charity has valued the benefit it receives from donated services as £93,800 (2016: £NIL). This is based on the open market value of the benefits received.

2. INCOME FROM DONATIONS AND LEGACIES

	Restricted funds 2017 £	Unrestricted funds 2017 £	Total funds 2017 £	<i>Total funds 2016 £</i>
Donations	54,683	51,571	106,254	9,543
Legacies	-	-	-	205
Grants	159,081	5,000	164,081	65,509
Gift aid	-	2,629	2,629	2,319
	<hr/>	<hr/>	<hr/>	<hr/>
Total donations and legacies	213,764	59,200	272,964	77,576
	<hr/>	<hr/>	<hr/>	<hr/>
<i>Total 2016</i>	<i>51,226</i>	<i>26,350</i>	<i>77,576</i>	
	<hr/>	<hr/>	<hr/>	

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LIMITED
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**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2017**

3. ACTIVITIES TO GENERATE FUNDS

	Restricted funds 2017 £	Unrestricted funds 2017 £	Total funds 2017 £	<i>Total funds 2016 £</i>
Fundraising	680	5,482	6,162	9,483
Fundraising - GSD Giant	130	7,142	7,272	5,164
	<u>810</u>	<u>12,624</u>	<u>13,434</u>	<u>14,647</u>
<i>Total 2016</i>	<u>23</u>	<u>14,624</u>	<u>14,647</u>	

4. INCOMING RESOURCES FROM CHARITABLE ACTIVITIES

	Restricted funds 2017 £	Unrestricted funds 2017 £	Total funds 2017 £	<i>Total funds 2016 £</i>
Conference	9,005	-	9,005	38,217
Subscriptions	10	685	695	765
Book sales	1,112	217	1,329	399
Walking courses	3,265	-	3,265	5,455
	<u>13,392</u>	<u>902</u>	<u>14,294</u>	<u>44,836</u>
Incoming resources from charitable activities	<u>13,392</u>	<u>902</u>	<u>14,294</u>	<u>44,836</u>

In 2016, of the total income from charitable activities, £765 was to unrestricted funds and £44,071 was to restricted funds.

5. INVESTMENT INCOME

	Restricted funds 2017 £	Unrestricted funds 2017 £	Total funds 2017 £	<i>Total funds 2016 £</i>
Investment income	-	61	61	120
<i>Total 2016</i>	<u>-</u>	<u>120</u>	<u>120</u>	

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6. FUNDRAISING TRADING

	Restricted funds 2017 £	Unrestricted funds 2017 £	Total funds 2017 £	<i>Total funds 2016 £</i>
Fundraising expenses	-	7,454	7,454	9,416
<i>Total 2016</i>	<u>5,625</u>	<u>3,791</u>	<u>9,416</u>	

7. DIRECT COSTS

	Charitable activities £	Total 2017 £	<i>Total 2016 £</i>
Conference	54,559	54,559	26,282
Euromac	6,396	6,396	8,468
Walking courses	2,951	2,951	1,435
Consultancy	39,500	39,500	-
Wages and salaries	21,000	21,000	-
National insurance	1,820	1,820	-
Pension cost	210	210	-
	<u>126,436</u>	<u>126,436</u>	<u>36,185</u>
<i>At 31 March 2016</i>	<u>36,185</u>	<u>36,185</u>	

8. ANALYSIS OF GRANTS

	Grants 2017 £	Total 2017 £	<i>Total 2016 £</i>
Grants, Charitable activities	<u>22,263</u>	<u>22,263</u>	<u>5,250</u>

In 2017 2 grants were made to institutions (2016: 1) and 7 to individuals (2016: 1).

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Grants to institutions were as follows:

	2017 £	2016 £
University College London	-	5,000
Brunel University	1,000	-
Royal College of General Practitioners	18,205	-
	19,205	5,000
Total	19,205	5,000

9. SUPPORT COSTS

	Charitable activities £	Total 2017 £	Total 2016 £
Rent	4,200	4,200	4,200
Office costs	3,714	3,714	7,145
Online services	1,075	1,075	3,396
Website and computer costs	39,728	39,728	761
Sundry expenses	519	519	445
Insurance	436	436	447
Printing, postage and stationery	8,156	8,156	2,959
Travel and accommodation expenses	13,227	13,227	6,859
Depreciation - office equipment	854	854	241
Accountancy & payroll	1,591	1,591	1,388
Independent examiners fee	2,190	2,190	2,800
Wages and salaries	33,600	33,600	33,600
National insurance	517	517	1,517
	109,807	109,807	65,758
	109,807	109,807	65,758
<i>At 31 March 2016</i>	<i>65,758</i>	<i>65,758</i>	

During the year ended 31 March 2017, the company incurred the following Governance costs: £3,781 (2016 - £4,188) included within the table above in respect of Charitable activities.

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10. NET INCOME/(EXPENDITURE)

This is stated after charging:

	2017	2016
	£	£
Depreciation of tangible fixed assets: - owned by the charity	854	241

Trustees received remuneration amounting to £NIL in the current year (2016 - £NIL).
During the year, no Trustees received any benefits in kind (2016 - £NIL).
During the year, no Trustees received any reimbursement of expenses (2016 - £NIL).

11. AUDITORS' REMUNERATION

The Independent Examiner's remuneration amounts to an Independent Examination fee of £2,190 (2016 - £2,800), and accountancy & payroll services of £1,591 (2016 - £1,388).

12. STAFF COSTS

Staff costs were as follows:

	2017	2016
	£	£
Wages and salaries	54,600	33,600
Social security costs	2,337	1,517
Pension costs	210	-
	57,147	35,117
	57,147	35,117

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

	2017	2016
	No.	No.
	2	1

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 charity were £34,117 (2016: £33,600).

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13. INTANGIBLE FIXED ASSETS

	Website development £
Cost	
At 1 April 2016	-
Additions	5,872
	5,872
At 31 March 2017	5,872
Carrying amount	
At 31 March 2017	5,872
<i>At 31 March 2016</i>	-

14. TANGIBLE FIXED ASSETS

	Office equipment £
Cost	
At 1 April 2016	3,029
Additions	2,695
	5,724
At 31 March 2017	5,724
Depreciation	
At 1 April 2016	2,308
Charge for the year	854
	3,162
At 31 March 2017	3,162
Net book value	
At 31 March 2017	2,562
<i>At 31 March 2016</i>	721

15. DEBTORS

	2017 £	2016 £
Trade debtors	160	3,710
Prepayments and accrued income	33,187	12,991
	33,347	16,701

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16. CREDITORS: Amounts falling due within one year

	2017	2016
	£	£
Other taxation and social security	18	18
Other creditors	5,714	4,456
Accruals and deferred income	5,156	2,957
	<u>10,888</u>	<u>7,431</u>

17. FINANCIAL INSTRUMENTS

	2017	2016
	£	£
Financial assets measured at amortised cost	<u>120,197</u>	<u>96,910</u>
Financial liabilities measured at amortised cost	<u>10,870</u>	<u>6,805</u>

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

Financial liabilities measured at amortised cost comprise accruals and other creditors

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

STATEMENT OF FUNDS - CURRENT YEAR

	Balance at 1 April 2016 £	Income £	Expenditure £	Transfers in/out £	Balance at 31 March 2017 £
Unrestricted funds					
General Funds - all funds	12,766	72,787	(81,303)	725	4,975
Restricted funds					
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
Conference	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>

STATEMENT OF FUNDS - PRIOR YEAR

	<i>Balance at 1 April 2015 £</i>	<i>Income £</i>	<i>Expenditure £</i>	<i>Transfers in/out £</i>	<i>Gains/ (Losses) £</i>	<i>Balance at 31 March 2016 £</i>
Unrestricted funds						
General Funds - all funds	1,699	41,859	(30,792)	-	-	12,766
	<u>1,699</u>	<u>41,859</u>	<u>(30,792)</u>	<u>-</u>	<u>-</u>	<u>12,766</u>

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

Restricted funds

Type 2 Pompe's	18,534	10,834	(12,043)	-	-	17,325
Type 5 McArdles	24,937	6,992	(13,865)	-	-	18,064
Type 3 Cori	7,322	231	-	-	-	7,553
Type 1 Von Gierke	4,809	-	-	-	-	4,809
Euromac	3,254	14,758	(18,012)	-	-	-
Awards for All	22	-	-	-	-	22
Type 6 Hers Fund	602	-	-	-	-	602
Hardship fund	3,792	-	(250)	-	-	3,542
Conference	10,680	27,505	(38,171)	-	-	14
Medical Advisory Board	2,108	-	(2,043)	-	-	65
Specialist Care Advisor	-	35,000	(1,433)	-	-	33,567
	<u>76,060</u>	<u>95,320</u>	<u>(85,817)</u>	<u>-</u>	<u>-</u>	<u>85,563</u>
Total of funds	<u>77,759</u>	<u>137,179</u>	<u>(116,609)</u>	<u>-</u>	<u>-</u>	<u>98,329</u>

SUMMARY OF FUNDS - CURRENT YEAR

	Balance at 1 April 2016 £	Income £	Expenditure £	Transfers in/out £	Balance at 31 March 2017 £
General funds	12,766	72,787	(81,303)	725	4,975
Restricted funds	85,563	227,966	(184,657)	(725)	128,147
	<u>98,329</u>	<u>300,753</u>	<u>(265,960)</u>	<u>-</u>	<u>133,122</u>

SUMMARY OF FUNDS - PRIOR YEAR

	Balance at 1 April 2015 £	Income £	Expenditure £	Transfers in/out £	Balance at 31 March 2016 £
General funds	1,699	41,859	(30,792)	-	12,766
Restricted funds	76,060	95,320	(85,817)	-	85,563
	<u>77,759</u>	<u>137,179</u>	<u>(116,609)</u>	<u>-</u>	<u>98,329</u>

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18. STATEMENT 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.

Euromac

EC DG Sanco (ref. 2012 12 14) via Euromac - contract to disseminate Euromac information throughout Europe.

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.

Conference

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.

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

Website Redevelopment Fund

Supporting the redevelopment of the charity's website

Patient Education and Empowerment

Supporting patients and families by providing family days.

Transfer between funds

The Euromac project finished during the year. The surplus funds were transferred 60:40 between the McArdle and general funds in line with charity policy.

19. ANALYSIS OF NET ASSETS BETWEEN FUNDS

ANALYSIS OF NET ASSETS BETWEEN FUNDS - CURRENT 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>

ANALYSIS OF NET ASSETS BETWEEN FUNDS - PRIOR YEAR

	<i>Restricted funds 2016 £</i>	<i>Unrestricted funds 2016 £</i>	<i>Total funds 2016 £</i>
Tangible fixed assets	-	721	721
Current assets	85,563	19,476	105,039
Creditors due within one year	-	(7,431)	(7,431)
	<u>85,563</u>	<u>12,766</u>	<u>98,329</u>

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NOTES TO THE FINANCIAL STATEMENTS
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20. PENSION COMMITMENTS

The Charity operates a defined contribution pension scheme. The assets of the scheme are held separately from those of the Charity in independently administered funds. The pension cost shown in note 12 represent the contributions payable by the Charity to these funds.

21. OPERATING LEASE COMMITMENTS

At 31 March 2017 the total of the Charity's future minimum lease payments under non-cancellable operating leases was:

	Land and buildings	
	2017	2016
	£	£
Amounts payable:		
Within 1 year	4,200	4,200
	<u><u>4,200</u></u>	<u><u>4,200</u></u>

22. RELATED PARTY TRANSACTIONS

There were no related party transactions for the year ended 31 March 2017.