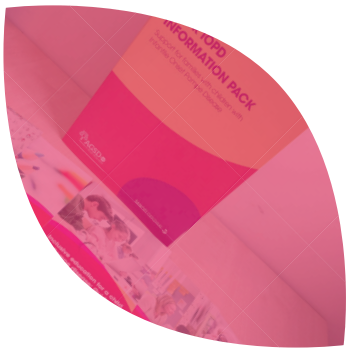
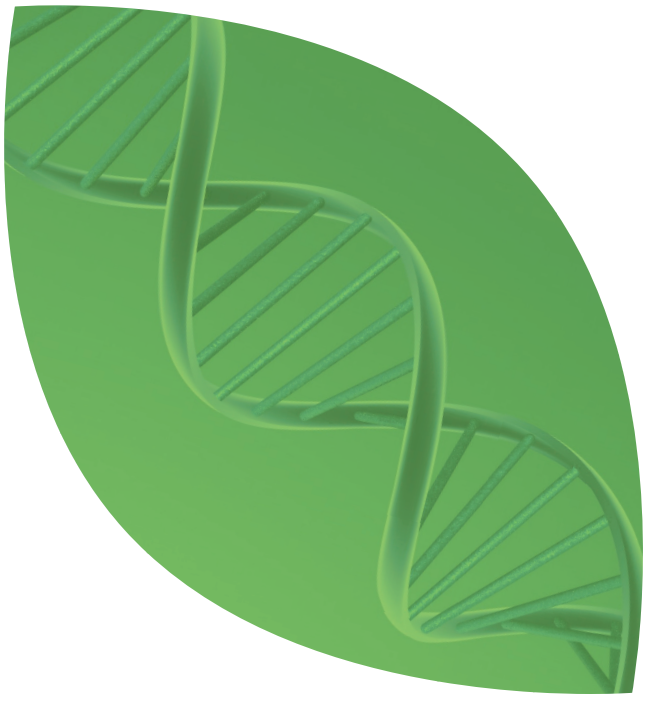
AGSD UK

Annual Report 2017-18





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FOREWORD

From very humble beginnings in 1986, AGSD-UK, has become an extremely effective and efficient organisation, supporting individuals and families living with Glycogen Storage Disease. This comes at a time when great improvements are being felt in many related disciplines, including medical research, diagnostics and the development of novel therapies.

AGSD-UK not only supports their member's non-medical needs, but it represents patients' interests within many other aspects of health and social services. Their staff are well known to the specialist services within NHS England, Wales, Scotland and Northern Ireland and regularly meet with NHS medical teams and commissioners. Being the only UK charity that supports all GSDs, they are invited to advise on the design of new therapies, clinical trials and a whole range of innovations to improve the lives of their patient and family community.

A major highlight of AGSD-UK's year is its annual conference for all stakeholders in the GSD community: patients, families, medical professionals, laboratory scientists and researchers, as well as nutrition, biotechnology and pharmaceutical companies. It is an event that my own staff regularly attends for a very rewarding experience, both professionally and socially.

It is amazing to me how an organisation, with so few resources, does so much for the GSD community. I know however that they are frustrated by their limitations and are striving to increase their capacity to help many more people living with the distressing effects of Glycogen Storage Disease.

Prof. Simon Heales

Department of Paediatric Laboratory Medicine
Great Ormond Street Hospital

AGSD UK Crisis Grants

" I just wanted to thank you again, the mattress and the protectors are great and my son's definitely starting to settle again. We've made some changes to positioning of the bipap and humidification too and all is really making a difference".
Mother of child aged 4.

Family Days

"Thanks for organising the get together between the families. It was a great opportunity to meet other families and share ideas. It's a good feeling knowing that you are not alone. I really appreciate it."
Mother of a child aged 8.

CHAIRMAN'S REPORT

Welcome to the AGSD-UK 2018 Annual Review. It has been another very busy year for the Trustee Directors, staff and volunteers. As always, the financial environment for all UK charities, particularly for those smaller rare disease charities such as ourselves, remains challenging. Despite this, we have continued to deliver sustainable year-on-year financial improvement helping us deliver services to our beneficiaries.

Our strategy in terms of income generation and expenditure is to carry forward only a small surplus each year, spending most of our in-year income on in-year services.

During the year the trustee board met three times in: May 2017, September 2107 and January 2018.

In addition a number of trustee board sub committees met throughout the year. We have had one resignation from the trustee board, Phil Prosser, due to family and personal pressures. However, I am delighted to report that we have appointed three new Trustee Directors; Jane Guy OBE, Heneage Legge-Bourke and Ailsa Arthur. One of the major objectives for last year was to further strengthen the trustee board and I believe that we now have a group of committed trustees with a broad mix of backgrounds and appropriate skill sets.

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, Jane Lewthwaite.

It is unfortunate that the spotlight has fallen on the charitable sector recently for the wrong reasons; aggressive fundraising tactics, data breaches and safeguarding issues come immediately to mind. All of these serious issues remind us 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 issues, and provide appropriate assurance to our members, funders and donors.

As well as hosting our annual AGSD-UK conference in Nottingham and a number of regional meetings, the charity was represented at three international conferences: World Symposium in San Diego, IGSD2017 in Groningem, and AGSD-US in Chicago. Attendance at events such as these adds to our store of knowledge about emerging developments in the field of glycogen

CHAIRMAN'S REPORT

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.

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.

The focus for the coming year will be in some cases more of the same – launch our new updated website, complete our Information Governance work and further develop our succession planning process, but a major area of activity will be seeking to identify and gain funding streams for specific pieces of work. Included are funds for one or more Specialist Care Advisors, the purchase of standardised IT equipment, topping up of the dwindling Hardship Fund, producing further publications/literature, investigating new technology to support glycogen storage disease sufferers – e.g. wearable applications that will support the condition, and of course funding to help patients and their families get together to share experiences.

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.

Mike Porter

WHAT WE DO

AGSD-UK would like to see all people with glycogen storage disease given the opportunity to lead full and productive lives. To help achieve this, this is what we do.....

Support and Advocate

We are always willing to support and be an advocate for those affected in any way by Glycogen Storage Disease.

Encourage Peer Support

Currently there are support groups for GSD 2a (Pompe), GSD 5 (McArdles) and the newly formed Cori Action Team (GSD 3). These groups provide a sense of belonging to a community of people with similar experiences, providing ideas and approaches that are helpful, along with a sense of validation. This year has seen some highly successful work accomplished, including the development and publishing of disease specific information leaflets and notably the popular walking course run by the McArdles group which was attended by people from all over the world.

Raise Awareness and Educate

On Rare Disease Day this year, members braved the snow and joined forces with Genetic Alliance, other charities and parliamentarians at the Houses of Parliament in a performance and display of unity with the One Voice choir outside Westminster. This was a great occasion to get the word out to the public and Members of Parliament. Members of AGSD-UK have been meeting with and talking to groups of student nurses. As a group directly affected by the disease, we are in the unique position to help professionals understand the experience of those affected as they go through the health system. Comments afterwards have included “absolute highlight of the course” and “so much was learnt”. This year an e-learning module was developed in collaboration with the Royal College of General Practitioners with the intention of providing a short introduction to GPs, hopefully improving early diagnosis and appropriate referrals. AGSD-UK supplies guides and leaflets on the different types of GSD, suitable for those affected, family, employers, schools and other youth organisations.

Collaborate

This year saw another highly successful conference at Nottingham with 185 members attending and 36 invited professionals, all with a view to improving care. Feedback from members was overwhelmingly favourable. Staff and members of AGSD-UK attended the International Glycogen Storage Disease conference in Groningen, The Netherlands this year. This gave one member from the UK the opportunity to run a networking session “Charting Experience of Myopathy in GSD 3” which was attended by delegates from all over the world. Throughout the year staff have been active in their collaboration with other UK patient organisations such as the UK LSD Collaborative, Muscular Dystrophy UK, and Genetic Alliance in order to benefit members. AGSD-UK also has close international connections, through executive positions within the International Pompe Association and the International Association for Muscle GSD, and our membership of EURORDIS.

Fundraise

Cyclists, runners and walkers have covered miles, enduring aching limbs and sore feet. Cakes have been baked and then burnt, all in an attempt to support AGSD-UK and its work. One successful member who deserves a mention is Deborah Corcannon, affected by McArdles; she completed the London Marathon and raised £3,000.

AIMS, MISSION AND VISION

AGSD-UK provides support and help for individuals and families affected by an ultra-rare condition known as Glycogen Storage Disease (GSD). Glycogen is a stored form of glucose, which is used as a fuel for energy. Glycogen Storage Disease occurs when there is an absence or deficiency of an enzyme needed to produce or break down glycogen. GSD primarily affects the liver and/or the muscles, including the heart.

The charity gives support to those with all GSD Types. There are currently 16 known Glycogen Storage Diseases; most have sub types and some have tiny numbers of people affected. Incidence, number diagnosed and age of diagnosis vary enormously.

AGSD-UK aims to help patients and their families affected by Glycogen Storage Diseases in a number of ways.

- Act as a patient and family contact and support group
- Provide information on request by phone or email
- Hold GSD-specific workshops
- Carry out, promote and/or support research and surveys into GSD
- Publish a newsletter for all stakeholders
- Create information and resource materials
- AGSD-UK organise an Annual Conference which usually takes place over two days in the autumn and is attended by people with GSDs, their families and many medical professionals, laboratory scientists and researchers

MISSION STATEMENT

Supporting people affected by GSD to live positively with their condition.

VISION STATEMENT

To become the primary and central focus for information and support, and driving positive change, for people affected by GSD.

FINANCIAL ACTIVITIES 2018

STATEMENT OF FINANCIAL ACTIVITIES INCORPORATING INCOME & EXPENDITURE ACCOUNT FOR THE YEAR ENDED 31 MARCH 2018

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

BALANCE SHEET AS AT 31 MARCH 2018

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

These financial statements are taken from the published accounts of AGSD-UK. The full accounts will be available to view on the charity commission website: http://apps.charitycommission.gov.uk (Search for charity number 1132271)

TREASURER'S REPORT

Results of the Year ending April 2018

The year 2018 saw income satisfactorily maintained at the same level of the previous year at £299,425 with expenditure encouragingly reducing from £265,960 to £232,536, a reduction of 13% due mainly to significantly lower website and computer costs reflecting our entering the final phase of the website development and in spite of higher conference costs which increased by 14%. It should be remembered, however, that the conference is your charity's most important activity at the heart of our mission. Overall support costs, including those relating to the website and computers reduced down to £88,234 from £109,807, a reduction of 20%.

Income less expenditure showed a surplus of £66,889, up from £34,793, an increase of 92% over the previous year and which enabled us to carry forward £133,122 resulting in total funds being carried forward of £200,011 at the end of the year, which represent our net assets and which showed an increase of 50%.

A note of caution should be sounded, nevertheless, as the balance between restricted funds and unrestricted funds tilts heavily towards the former which account for 90% of the total. Whilst this percentage is still high, there was a small improvement in this ratio. Cash at bank and in hand amounted to £186,284 at the end of the year – a significant increase of 82% and debtors decreased by 78% demonstrating the efforts to collect donations in a more timely fashion.

The current year

As mentioned earlier, restricted funds represent by far the greatest proportion of our funding, so one of our most important financial targets in the current year is to improve this ratio between restricted and unrestricted funds so that we have greater freedom to allocate our resources where they are most needed and likely to produce the best results.

Whilst we are pleased that cash at the bank and in hand is at a comfortable level, we will monitor this closely to ensure that our funders may recognize that we are spending their donations on the projects for which they funded us.

We expect higher employee costs during the year as we increase our workforce to enable us to provide the proper level of support for our on-going efforts. This means that we will strive to seek further funding. We will also be keeping a close watch on how we cost out to our various projects appropriate central costs, which will inevitably grow with an increased workforce.

So, whilst your charity is currently in sound financial health we will not be complacent, as without continuing and increased funding we will not be able to carry out the work we do. Our effort therefore, to increase our funding base continues and is producing good results, however close attention is being paid on how to further improve it, as this funding is vital in enabling us to carry out our mission.

Heneage Legge-Bourke
Hon. Treasurer

ENSURING GOOD GOVERNANCE

We currently have seven trustees with a range of skills across management, marketing, finances and IT. Four trustees have experience and first-hand knowledge of glycogen storage disease either as a sufferer, family member or primary carer. Where necessary they seek advice from experts. All trustees are ambassadors for the charity and act in the charity's best interest to meet the aims and objectives of the charity and to ensure it is of public benefit.

Trustees take full responsibility for managing the finances including monitoring their performance with good budgetary and financial controls in place to keep funds safe. They have agreed a strategic plan for income generation and appreciate how important it is to manage our limited resources carefully and efficiently and with reasonable skill and care.

Trustees are of course accountable to the Charity Commission and Companies House but also as an employer of staff have policies in place to ensure we keep up to date with relevant laws such as for pensions, employment and health and safety. We are also accountable to our membership, especially at the annual conference and AGM, and to ensure the greatest transparency provide regular newsletters, hold meetings and keep our website up to date.

Working with very vulnerable adults and children, we have robust policies in place for safeguarding and protection. We have many policies in place but the key ones are Acceptable Use of IT, (including preparing for the new GDPR), Conflicts of Interest, Contracts of Employment, Financial Planning, Risk Assessment, Safeguarding and Equality & Diversity. Complying with regulation and the law, and monitoring our policies is very important for good governance.

As a charity, with staff who support people with serious health impairments, which includes some of our volunteers, we recognise the importance of continuing support and care to them all.

Underpinning the day-to-day running of the charity and the development and implementation of the strategic plan is our determination to abide by recommendations of the Charity Commission and to comply with all relevant regulations.

AGSD UK Signposting and Advice

"My daughter is a healthy, tall teenager with GSD 3 and currently taking no medication. I know she is more the exception rather than the rule but I never thought that this would be the outcome all those years ago after diagnosis. The AGSD does a wonderful job, and I do hope to meet all the team again soon."
Mother of child aged 14.

THE SPECIALIST CARE ADVISOR [SCA]

The Pompe SCA is tasked with these aims:

- To make a positive difference to the lives of people affected by Pompe disease through providing non-clinical advice, support and information to patients, parents and care-givers.
- To enable people affected by Pompe Disease to access a range of non-clinical services with the object of enhancing and improving their quality of life.
- To provide advice and support for all referred individuals and families on a broad range of quality of life issues including; benefits, housing, finance, aids, mobility and travel, grants, counselling, access, safety, education and employment.
- To ensure people who need the service are not excluded.

The post has existed for two years and has transformed the support we are able to offer. The role is primarily reactive, which means it responds to expressed needs. It is also person-centred, which means it is lead by the users themselves and not imposed on them.

Currently the majority of help sought is related to disability benefits. Basic checks are conducted, forms obtained and completed with the service user. Importantly, AGSD UK can provide professional supporting letters as evidence.

Advocacy is the second most common reason for referral, this means making phone calls and emailing on behalf of people, with their permission, to chase up care, services or the help they need. This is most important for people struggling to navigate complex care needs whilst also acting as a carer or looking after their own health. Help has been provided in a very wide variety of areas including; housing, Disabled Facilities Grants, Education and Health Care Plans, employment, travel, home care, Occupational Therapy, equipment and aids as well as falls prevention.

The SCA helps to produce much needed information resources including children's books and school resource pack, as well as coordinating the Pompe Support Team's development of a Risk Alert card and Medical Overview booklet.

Time is also spent helping people navigate their way through a complex pathway towards, and especially after, diagnosis. The SCA can enable links to groups, meetings, contacts with another person with the same diagnosis, a chance to talk about options and provide accurate information about managing Pompe disease.

Around 70% of referrals come from individuals themselves. The balance comes from specialist nurses or other professionals.

The SCA maintains relationships with all the Highly Specialised Metabolic Centres in the UK and attends clinics where possible. The SCA reports to the Trustees three times per year and reports monthly to the Pompe Support Team.

CHARITY MILESTONES

Here are some of our milestones

1929: Von Gierke described an illness now called Glycogen Storage Disease I (von Gierke's Disease).

1986: Founded AGSD-UK by Ann Phillips and Sue Del Mar, mothers of children affected by Glycogen Storage Disease.

1988: Registered as a charity with the Charity Commission. Organised the first family conference.

1996: Awarded a grant to a research team at Erasmus Medical Centre, Rotterdam. The bioreactor developed with this grant proved the principle of Enzyme Replacement Therapy for Pompe disease.

1997: Funded the involvement of an exercise physiologist at the McArdle Clinic.

1998: Co-founded the International Pompe Association with support groups from other nations

1999: Published agsd.org.uk web site dedicated to disseminating information on GSDs.

2005: Appointed part time patient liaison officer for Pompe disease in co-operation with Muscular Dystrophy UK. Sponsored research into "Model Systems for Developing Therapies for McArdle Disease".

2007: Appointed AGSD-UK Family Support Officer for Pompe, funded by Sanofi-Genzyme and based at St Mary's Hospital, Manchester.

2009: AGM agreed that the association should convert to a company limited by guarantee.

2010: Recruited first paid employee and opened office base in Droxford, Hampshire.

2012: Produced a short film "Hope in the Genes" to raise awareness of AGSD-UK

2016: Appointed a Specialist Care Advisor – Pompe. Wrote and published first in series of "Medical Overview" booklets to support decisions in primary care.

2017: Developed two eLearning modules for GSDs now hosted by the Royal College of General Practitioners website. Wrote and published a book "101 Tips for a better life with Pompe Disease".
New logo adopted.

STATISTICS

Financial help for our members

- 18 successful benefit applications made generating over £90,000 for our members giving an average of £98 per week extra income to individuals
- £5,120 raised in grants for individuals (internally and externally)
- 1 grant for a member of £3,700

AGSD-UK

- 1,646 people now registered with AGSD-UK
- 90 new patients/families registered in 2017
- 310 UK McArdle patients
- 616 UK patient and parent/care-giver registered contacts – 1,062 worldwide
- 1,000 UK contacts 588 overseas – 1,588 total
- 185 people attended our conference at the East Midlands Conference Centre last October
- In the last 5 years approx. 1,000 have attended our conferences

You Tube Videos

- Views of our film "Hope in the Genes" reached over 8,300
- "Walking with McArdles" had over 1,700 views and the collection of all AGSD-UK videos for McArdle have had over 10,000 views

International Key Opinion Leaders in GSD - Close collaboration with KOLs in countries including: Australia, Canada, Denmark, France, Germany, Italy, The Netherlands, Spain, Taiwan, USA and New Zealand

NHS Services, including:

- Specialised Services for Metabolic disorders
- Highly Specialised Lysosomal Storage Disorders Service
- Highly Specialised McArdle's Disease Service
- Commercial Medicine's Unit – Homecare Medicines and Services

Other UK Charities - Rare Diseases UK, Genetic Alliance, UK LSD Collaborative, Muscular Dystrophy UK, Neuromuscular Centre MC WInsford, Medics for Rare Diseases, Children's Liver Foundation

Worldwide organisations - International Pompe Association, International Association for Muscle Glycogen Storage Disease

Industry - We build relationships with **care services** such as Home Care companies. We meet with the **pharmaceutical industry, biotechnology companies**, **nutrition suppliers** such as Nutricia and Vitaflo. Also **device and equipment manufacturers**.

European Organisations - EURORDIS, European Medical Agency

Decision Makers - NHS-England (NICE), NHS-Scotland (SMC), NHS-Wales (WHSSC), Health and Social Care in Northern Ireland (HSC)

OUR SINCERE THANKS

We take this opportunity to thank all our fundraisers. We are grateful to all our supporters who have used the following organised events to raise sponsorship money:

- London Marathon
- London Vitality 10k run
- Prudential Ride London-Surrey cycling events
- BigFunRun
- South Coast Challenge
- Lyke Wake Walk
- Royal Parks Half Marathon
- Camping and Caravanning Club – Feast of Lanterns

And we thank The Hive Group and Tesco, employers of our members, who give matched funding and raise significant funds themselves.

Our major donors who support our work are generally biotechnology or specialist nutrition companies:

- Amicus Therapeutics
- Audentes Therapeutics
- Sanofi-Genzyme
- Valerion Therapeutics
- Vitaflo

Trusts and Foundations who supported us and our members throughout the year:

- Roald Dahl Foundation
- St James Place Foundation
- Campbell Burns Metabolic Trust
- Buttle UK
- Hudson Charitable Trust
- Persimmon

We thank all of those who volunteer their time to AGSD-UK. Together the value of their donated services was an amazing **£72,310 during the 2017/18 financial year**. AGSD-UK could not exist without the wonderful work of our team of GSD Co-ordinators who we would also like to thank sincerely,

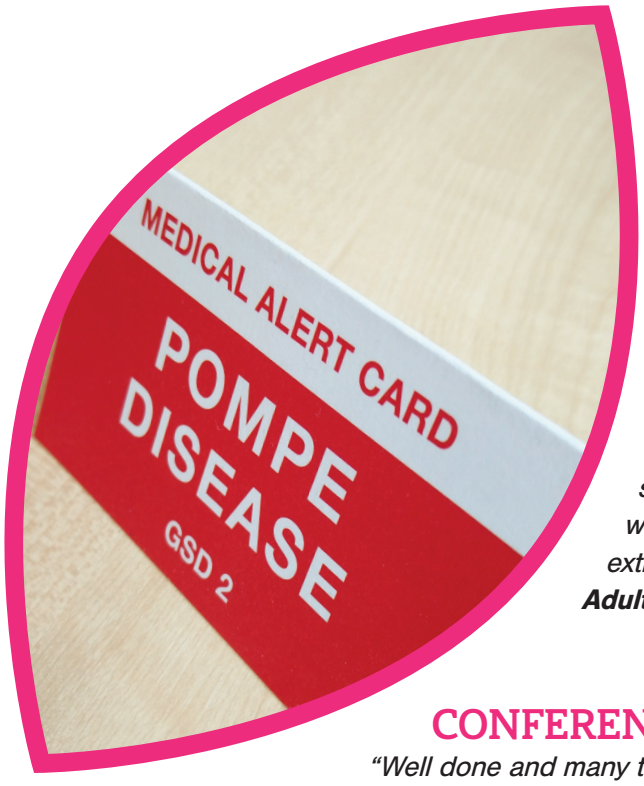
Online giving through JustGiving and VirginMoneyGiving reached over **£26,000**

QUOTES FROM STAKEHOLDERS

THE NEW IOPD (Infantile Onset Pompe Disease) SCHOOL RESOURCE PACK

This pack was created in partnership with Sanofi Genzyme.

"It was very, very full of information and had everything I needed in the pack. It is in depth and I read the pack to prepare for meetings with the school so I knew exactly what to expect and exactly what to ask. It had questions in there that I had not even thought of asking or considered." ***Mother of child aged 10.***



THE NEW RISK ALERT CARD

The Risk Alert card was created by the Pompe Support Team and reviewed by medical advisors.

"I took the card with me before my surgery and showed it to the anaesthetists and surgeon. They were very interested and said it was extremely helpful. It gave me more confidence too".
Adult with Pompe aged 37.

CONFERENCE 2017

"Well done and many thanks to Jane and Allan for all your hard work at and running up to the conference. It was fantastic as always".
Father of family of three children.

BENEFIT ASSISTANCE

"I have been awarded the Carers Allowance, thanks to your help and support, it is a great relief."
Mother of a child aged 10

"Just to let you know we went to the tribunal today and WON!! We started off with 1 point, then gained another 4 re the mandatory reconsideration, today she was awarded 14 in total. They gave her the PIP enhanced rate and standard mobility! Thank you so much for all your assistance, of which we appreciated".
Mother of a child aged 10

Admistrative Information

Registered office
Black Country House, Rounds Green Road,
Oldbury, West Midlands, B69 2DG
Company Registration number: 06981121
Charity Registration number: 1132271

Office Address
Old Hambledon Racecourse, Droxford,
Southampton, Hampshire, SO32 3QY.
Tel: 0300 123 2790.
Website: www.agsd.org.uk

Current Trustees
Stuart Alderson
Ailsa Arthur
Jane Guy, OBE
Nicholas Jones
Heneage Legge-Bourke, Treasurer
Jayesh Pindolia
Michael Porter, Chairman

Staff
Allan Muir, Charity Director
Jackie Henson, Administrator
Jane Lewthwaite, Specialist Care Advisor

Aims and Principles
“The relief of sickness, particularly of persons suffering from any form of Glycogen Storage Disease”.

Relationships and Networks
We maintain links and relationships with a wide variety of organisations and groups in order to ensure; Our members are updated about new treatments and access services. We can represent and advocate for our members. Our members and stakeholders’ voices are heard.

New publications
McArdles at Work and McArdles at School
McArdles total 8 publications
Pompe 101 Tips – orders from around the world
Translations in German, Italian, French
Medical Overview produced by Pompe Support Team to empower patients
Information pack produced for schools and families
Pompedoo – a children’s book for friends and siblings

AGSD UK
Association for Glycogen Storage Disease (UK) Ltd