

TRUSTEES' REPORT

FOR THE Period 1st April 2021 to 31st March 2022

The Trustees present their annual report together with the financial statements of the company for the period 1st April 2021 to 31st March 2022. The Trustees confirm that the Annual report and financial statements of the charitable company comply with the current statutory requirements, the requirements of the charitable company's governing document and the provisions of the Statement of Recommended Practice (SORP) applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102) (effective 1 January 2015) as amended by Update Bulletin 2 (effective January 2019).

Objectives and activities

a. Objects

The objects of the Pompe Support Network as recorded in its CIO Constitution, are:

1. TO RELIEVE SICKNESS OF CHILDREN AND ADULTS SUFFERING FROM POMPE DISEASE IN THE UNITED KINGDOM AND THROUGHOUT THE WORLD, IN PARTICULAR BUT NOT EXCLUSIVELY BY: (A) CONTRIBUTING TO THE ADVANCEMENT OF QUALITY RESEARCH & EDUCATION IN RESPECT OF POMPE DISEASE; AND (B) PROVIDING INFORMATION, ADVICE AND SUPPORT TO SUCH INDIVIDUALS, THEIR FAMILIES AND CARERS BY SUCH MEANS AS THE TRUSTEES MAY DETERMINE
2. TO RELIEVE THE NEEDS OF BEREAVED FAMILIES WHO HAVE LOST FAMILY MEMBERS TO POMPE DISEASE IN THE UNITED KINGDOM BY SUCH MEANS AS THE TRUSTEES MAY DETERMINE

The pompe support Network works to protect and promote the best interests of persons living with Pompe disease.

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 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 Pompe Support Network (PSN) acts as a vehicle of communication on Pompe Disease related matters by publishing and distributing relevant material. It contributes to the

advancement of treatments and cures through supporting research, studies, and trials. It acts as a focus for educational, scientific, and charitable activities related to Pompe disease. The PSN networks closely with other national and international organisations that support Pompe disease and other related conditions, including Glycogen Storage Diseases (GSDs), Lysosomal Storage Disease (LSDs) and neuromuscular diseases (NMDs).

c. Activities undertaken to achieve objectives

The main activities are the support of patients and families; the organising of online or face-to-face meetings to promote the understanding of Pompe disease; the publication of a regular newsletter; the provision of information about Pompe Disease through publications, video, and audio media, and through our web site and social media. PSN also provides grants to research bodies and individuals. These activities support the objects by assisting people living with Pompe disease by encouraging and supporting research into the disease and by informing the Pompe community and by educating the medical profession and other members of the public about the disease.

d. Grant-making policies

Currently the Pompe Support Network does not have sufficient funds to provide grants to support research projects, however, the PSN does support research by applying knowledge gained and sourced from the Pompe community. The PSN does occasionally make small grants to individual applicants for personal expenses related to their disability or care, where statutory services are unable to provide equipment or reimburse health-related expenses.

Achievements and performance

a. Review of activities

Our strategic plan outlined our aims:

- Act as a focus for the UK Pompe community
- Provide appropriate and well-informed non-medical advice
- Provide accessible and clear supply of information for all stakeholders
- Provide timely information relating to new medical interventions
- Promote, support, and publish research relevant to Pompe disease
- Promote research into medical treatments and devices for Pompe disease.
- Provide independent advice relating to clinical studies for Pompe disease
- Hold a print and online library of published works pertinent to Pompe disease.
- Encourage meetings to exchange information between stakeholders.
- Promote early diagnosis of Pompe disease
- Support UK neonatal screening for Pompe disease
- Promote public awareness and understanding of Pompe disease

We have continued to make progress in all areas, some examples are listed below.

Website

Our communications manager has now become a part-time staff member and has continued to develop and maintain the Pompe Support Network website, www.pompe.uk. It is becoming a highly valued resource containing a growing number of podcasts and

videos. These are designed to both inform individuals and families with a new diagnosis of Pompe and raise awareness of the condition and its effect on peoples' lives.

We have added two new services to our website. We now offer social care and benefits advice through our volunteer Wayne Belfitt, a qualified social worker. Additionally, we offer a counselling service through a professional counsellor, Caroline Finill.

Webinars, Video and Audio projects

During this period, we recorded and published three podcasts for our Pompe Voices collection that are now available in our online library.

We filmed five short films depicting the lives of four Pompe individuals and one family caring for their child who was diagnosed with Pompe disease during the Covid-19 lockdown. The films were produced to a high professional standard using a film crew and directed by Jamie Muir, a young film director who himself lives with late-onset Pompe. These films were premiered on 5 separate occasions, starting on Rare Disease Day, 28th February 2022. The fifth and final film was shown on 27th March 2022. Each on-line premiere was attended by members of the Pompe community.

Fundraising

Public donations continue to be received, but no fundraising events have been organised due to covid-19 restrictions and the small return that they offer.

Grant Applications

We have once again been successful with our grant applications several biotechnology companies although several payments were received outside of our financial year and are not reported in the accounts for this financial period. The major proportion of funds was allocated to the PompAbility film productions which required more than the original budget estimate.

We received considerable donations-in-kind from the film crew, film director and film editor which provided us with a high-quality film series at a very affordable price.

Networking and collaborative working

Allan Muir is a founder member of the UK LSD Collaborative, an informal group including 8 UK charities supporting Lysosomal storage disorders, of which Pompe disease is one. The collaborative meets several times each year to discuss topics of mutual interest and to meet with healthcare professionals located at each of the NHS Highly Specialised Centres for Lysosomal storage diseases. There are 8 such centres in England, one in Wales and an Inborn Metabolic Disorder network in Scotland.

Conferences and Meetings

Our Chair, Allan Muir, has attended several international meetings on behalf of the PSN and visit reports are given to the Trustees and published on the website for the benefit of Pompe community.

Allan Muir attended virtual conferences and symposia held by the Society for the Study of Inborn Errors of Metabolism (SSIEM), The WORLD Symposium and joined a small number of online conferences.

PSN supported a patient community survey operated by a market research company, Acaster Lloyd, funded by Amicus Therapeutics. The results were submitted as a poster presentation to both the World Muscle Society conference in September 2021 and the WORLD Symposium in February 2022. Allan Muir presented the posters at each event.

Representation to Regulatory Bodies

Pompe Support Network was again asked by the National Institute for Health and Care Excellence (NICE) to consult on applications for a new drug application for Pompe disease. The drug, Cipaglucosidase Alpha with Miglustat, is under development by Amicus Therapeutics. Allan Muir submitted the Scoping forms and attended the Scoping committee meeting on behalf of the Pompe community.

Diagnosis and Neonatal Screening

Our Chair, Allan Muir has been a member of the Patient Advocacy for Newborn Screening group for many years; that group has since morphed into the Archangel Newborn Screening Alliance and Pompe Support Network is an active member of the alliance and the campaign to add more rare diseases to the list of conditions screened for at birth under the UK National Screening Programme.

Allan Muir was invited to join an advisory board for a European collaboration that has five years of funding to research designed to “Shorten the path to rare disease diagnosis by using newborn genetic screening and digital technologies”.

Research

PSN does not directly fund research, but we are looking to facilitate further studies into medical devices that could help people with Pompe disease. For example, we are beginning to explore the hypothesis that Electrical Muscle Stimulation may benefit people with Pompe, and we are exploring activities to improve the mental wellbeing of our community.

Financial review

a. Going concern

Since the foundation of the Pompe Support Network CIO, relationships with funders have grown such that the trustees believe that there will be no adverse effects on income arising from the Covid-19 pandemic. The CIO has cash resources and has no requirement for external funding. At the date of signing the accounts the unrestricted reserve stands at £3,534.87. The trustees have reasonable expectation that the CIO has adequate resources to continue in operational existence for the foreseeable future. They continue to believe the going concern basis of accounting is appropriate in preparing the annual financial statements.

b. Reserves policy

The CIO holds funds that are restricted in expenditure in support of individual projects. The general reserves are used to support the on-going activities of the CIO. The trustees' future focus will be on increasing income while tightly managing costs.

In line with most small charities, Pompe Support Network aims to spend most of the funds raised during any given financial year for the benefit of the UK Pompe community 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.

c. Investment policy and performance

The Pompe Support Network holds all cash reserves in bank deposit accounts thus eliminating investment risk and minimising any other risk to the reserves. No long-term deposits are made as it is anticipated that the reserves will continue to be called upon to support a high level of activity.

Structure, governance, and management

a. Constitution

The Pompe Support Network is registered with the Charity Commission as a Foundation model Charitable Incorporated Organisation (CIO). As such, the only voting members are the charity trustees. The company is constituted under its CIO Constitution dated 22nd September 2019 with registered charity number 1186383. The principal object of the CIO is to provide " TO RELIEVE SICKNESS OF CHILDREN AND ADULTS SUFFERING FROM POMPE DISEASE IN THE UNITED KINGDOM AND THROUGHOUT THE WORLD".

b. Methods of appointment or election of Trustees

The management of the CIO is the responsibility of the Trustees who are elected and/or co-opted under the terms of the CIO Constitution. Any member of the Pompe community 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 a future meeting of Trustees.

c. Organisational structure and decision-making policies

The Pompe Support Network is a *foundation* model CIO; the existing trustees elect new members to 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.

The Board of Trustees delivers the strategy through staff and a small number of volunteers.

d. Pay policy for key management personnel

The company currently has one part-time member of staff, the Communications Officer. The remuneration for key management posts is benchmarked at or below market rate prior to appointment and is reviewed by Trustees annually.

e. Risk Management

The Trustees have assessed the major risks to which the CIO is exposed. The Trustees are satisfied that systems, procedures and plans are in place to mitigate exposure to major risks.

Plans for future periods

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

Statement of Trustees' responsibilities

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

The Charity Commission requires the Trustees to prepare financial statements for each financial year. The Trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the status of the CIO and of its incoming resources and application of resources, including its income and expenditure, for that period. In preparing these financial statements, the Trustees are required to:

- Select suitable accounting policies and then apply them consistently.
- Observe the methods and principles of the Charities SORP (FRS 102).
- Make judgments and accounting estimates that are reasonable and prudent.
- State whether applicable UK Accounting Standards (FRS 102) have been followed, subject to any material departures disclosed and explained in the financial statements.
- Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the CIO will continue in business.

The Trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the CIO's transactions and disclose with reasonable accuracy at any time the financial position of the company and enable them to ensure that the financial statements comply with Charity Commission regulations. They are also responsible for safeguarding the assets of the CIO and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Approved by order of the members of the board of trustees on

19th January 2023

And signed on their behalf



Allan Muir
Chair of Trustees

Charity No. 1186383

43a North Lane
Buriton
Petersfield
GU21 5RS

Pompe Support Network
for the year ending 31 March 2022

Prepared by:
Miss S - Accounting for Purpose CIC



Pompe Support Network - year ending 31 March 2022
Income and Expenditure

Charity No. 1186383

Income:			
	£	£	£
Donations		9,439.83	
Donations in Kind		57,550.00	
Grants			
Restricted	9,001.03		
Unrestricted	<u>3,534.87</u>		
		<u>12,535.90</u>	
Total Income			79,525.73

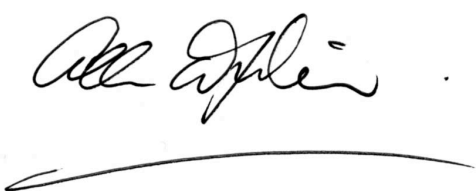
Expenditure:			
	£	£	£
Direct Expenses:			
Projects	55,070.84		
Public Speakers	-		
Awareness & Collaborative Meetings	-		
IT Consulting & Website Development	500.00		
Fundraising	<u>-</u>		
		55,570.84	
Administrative Expenses:			
Advertising & Marketing	-		
Management/Strategic Support	34,000.00		
Consultancy	6,612.00		
Salaries	18,000.00		
Pension	310.80		
Staff Training	-		
Travel	548.70		
Telephone & Internet	-		
Postage, Freight & Courier	13.97		
Printing & Stationery			
IT Software and Consumables	848.42		
Audit & Accountancy fees	2,353.80		
Professional Fees	520.00		
Subscriptions	163.70		
Sundry	-		
Bank Fees	31.84		
Foreign Exchange	<u>- 265.31</u>		
		<u>63,137.92</u>	
Total Expenditure			118,708.76

Excess of Income over Expenditure	- 39,183.03
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Fixed Assets	1,878.97
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Restricted Reserves	-
Unrestricted Reserves	6,898.35

Signed by the Chair of Trustees on behalf of all the Trustees:

Signature:  Name: Allan Muir

Date of Approval: 19 January 2023

Pompe Support Network - Charity Number 1186383
YE 31Mar22 compared with PE 31Mar21

Income:		YE 31Mar22		PE 31Mar21	
		£	£	£	£
Donations			9,439.83		5,901.03
Donations in Kind			57,550.00		15,500.00
Grants					
	Restricted	9,001.03		29,069.22	
	Unrestricted	<u>3,534.87</u>		<u>32,821.77</u>	
			<u>12,535.90</u>		<u>61,890.99</u>
Total Income			79,525.73		83,292.02
Expenditure:					
		£	£		£
Direct Expenses:					
	Projects	55,070.84		766	
	Public Speakers	-		4,000	
	Awareness & Collaborative Meetings	-		3,600	
	IT Consulting & Website Development	500.00		16,830.00	
	Fundraising	<u>-</u>		<u>502</u>	
			55,570.84		25,697.91
Administrative Expenses:					
	Advertising & Marketing	-		1,764.77	
	Management/Strategic Support	34,000.00		2,800.00	
	Consultancy	6,612.00		-	
	Salaries	18,000.00		-	
	Pension	310.80		-	
	Staff Training	-		322.52	
	Travel	548.70		788.32	
	Telephone & Internet	-		45.00	
	Postage, Freight & Courier	13.97		35.42	
	Printing & Stationery	-		92.25	
	IT Software and Consumables	848.42		2,950.21	
	Audit & Accountancy fees	2,353.80		45.00	
	Professional Fees	520.00		200.00	
	Subscriptions	163.70		375.55	
	Sundry	-		58.00	
	Bank Fees	31.84		141.55	
	Foreign Exchange	<u>- 265.31</u>		<u>15.17</u>	
			<u>63,137.92</u>		<u>9,633.76</u>
Total Expenditure			118,708.76		35,331.67
Excess of Income over Expenditure		-	39,183.03		47,960.35
Fixed Assets			1,878.97		1,878.97
Restricted Reserves			-		10,870.70
Unrestricted Reserves			6,898.35		35,210.68

Pompe Support Network - year ending 31 March 2022

Assets and Liabilities

Charity No.

1186383

Assets					
				£	£
Assets retained for the charity's own use					
20-Jan-21	Ikonic Tecknology - HP ProBook		849.99		
04-Feb-21	techINN - laptop		<u>1028.98</u>		
				1,878.97	
Bank					
	GBP	7,953.14	Restricted -	Unrestricted 7,953.14	
	Wise USD	207.86	-	207.86	
	Wise GBP	109.71	-	109.71	
	Paypal	<u>642.58</u>	-	<u>642.58</u>	
			-	8,913.29	8,913.29
Total Assets					10,792.26

Liabilities					
				£	£
Wages Payable - Payroll					
				1,576.24	
PAYE Payable					
				362.92	
Pensions Payable					
				<u>103.60</u>	
					2,042.76
Total Liabilities					2,042.76

Signed by the Chair of Trustees on behalf of all the Trustees:

Signature:



Name:

Allan Muir

Date of Approval:

19 January 2023

Pompe Support Network
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Charity No. 1186383

43a North Lane
Buriton
Petersfield
GU21 5RS

Pompe Support Network
for the year ending 31 March 2022

Prepared by:
Miss S - Accounting for Purpose CIC



Pompe Support Network - year ending 31 March 2022
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Pompe Support Network - year ending 31 March 2022

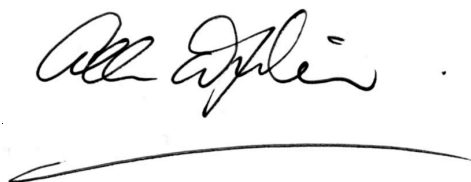
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Charity No. 1186383

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Name:

Allan Muir

Date of Approval:

19 January 2023

Pompe Support Network
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