

TRUSTEES' REPORT

FOR THE Period 1st April 2023 to 31st March 2024

The Trustees present their annual report together with the financial statements of the company for the period 1st April 2023 to 31st March 2024. 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.

Personnel

In January 2023 the Pompe Support Network recruited Mrs Hülya Apaydin as our part-time CEO, contracted to work 20 hours per week. Hülya brings a wide range of professional and personal experience to the role. She was previously a Trustee of the PSN, a position she resigned from at the same time.

Website

The Pompe Support Network website, www.pompe.uk 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 offer social care and benefits advice through our volunteer Wayne Belfitt, a qualified social worker and Trustee of Pompe Support Network. Additionally, we offer a counselling service through a professional counsellor, Caroline Finill who works at Psychology Partners.

Publications

Our inspirational book, "This Little Thing I Do", was published in 2023. It was created, published and distributed to members of the UK Pompe community thanks to a grant from the National Lottery.

We also published a children's book, "Leo and the Floppy Sloth", written by the mother of a child with Pompe disease. All cost of the publication were covered by Pompe Support Network, and it has been made available to purchase online through our website.

Fundraising

Public donations continue to be received, but no fundraising events have been organised due 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.

We received considerable donations-in-kind from trustees and volunteers.

Networking and collaborative working

Allan Muir is a founder member of the UK LSD Collaborative, a recently formalised Charitable Incorporated Organisation 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.

During this period Allan Muir stepped down as vice-chair and member of the International Pompe Association (IPA) and our CEO, Hülya Apaydin became an IPA board member in his place.

Conferences and Meetings

Allan Muir and Hulya Apaydin attended the WORLD Symposium in San Diego where the charity was allocated a booth, allowing us to share our literature and discuss our work with many delegates from around the world.

Allan Muir and fellow Trustee, Kevin Annesley, were invited to attend a Pompe Masterclass in Manchester, primarily for young medics less familiar with Pompe. Kevin was asked to describe the story of his lengthy diagnostic odyssey with the audience. It was organised by the team at the Royal Salford Hospital. Prof Mark Roberts later wrote:

"Thanks to you all I think the meeting went really well and I have already had requests for attachments at Salford and potential research collaborations."

"Kevin your story as a patient was inspiring and with Val and Allan's lectures and questions ensured we remained patient focussed."

The meeting was a great opportunity to network with UK and international Healthcare Professionals and homecare company representatives.

AM was invited to speak (virtually) to the European Tay-Sachs and Sandhoff family conference on 29th November. They were interested to hear about the Pompe experience in the 12 months following the commercialisation of Myozyme; they are soon to have a new drug authorised and want to know what to expect.

Representation to Regulatory Bodies

Pompe Support Network was 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, was then under development by Amicus Therapeutics. Allan Muir submitted presented evidence to the NICE meeting on behalf of the Pompe community. The drug was subsequently approved by NICE for patients in England.

Allan Muir also represented the Pompe community in Wales to the Welsh regulators All Wales Medicines Strategy Group (AWMSG) who have also approved both next generation Enzyme Replacement Therapies.

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 UK Newborn Screening Collaborative and Pompe Support Network is an active member of the group and its campaign to add more rare diseases to the list of conditions screened for at birth under the UK National Screening Programme. Allan and Hülya Apaydin both attended meetings of this group throughout the period.

Allan Muir has continued to represent the Pompe community on the Screen4Care advisory board; 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

Pompe Support Network 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 continue 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 £38,686. 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.

Trustees serving during this period

The following individuals served on the board of trustees:

Allan David John Muir	Chair	
Kevin William Annesley	Trustee	
Barbara Jane Muir	Trustee	
Kevin John O'Donnell	Trustee	
Hülya Apaydin	Trustee	Resigned 15 th January 2024
Wayne Belfitt	Trustee	
Malcolm Knightly	Trustee	Appointed on 29 May 2023

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

23rd January 2025

And signed on their behalf



Allan D J Muir
Chair of Trustees

Charity No. 1186383

43a North Lane
Buriton
Petersfield
GU21 5RS

Pompe Support Network
for the year ending 31 March 2024

Prepared by:
Miss S - Accounting for Purpose CIC



Pompe Support Network - year ending 31 March 2024
Income and Expenditure

Charity No. 1186383

Income:			
	£	£	£
Donations		8,780	
Donations in Kind		22,500	
Grants			
Restricted	18,000		
Unrestricted	<u>22,616</u>		
		<u>40,616</u>	
Total Income			71,896

Expenditure:			
	£	£	£
Direct Expenses:			
Projects	6,956		
Public Speakers	-		
Awareness & Collaborative Meetings	-		
IT Consulting & Website Development	-		
Other Direct Expenses	1,214		
Fundraising	<u>-</u>		
		8,170	
Administrative Expenses:			
Advertising & Marketing	62		
Management/Strategic Support	22,500		
Consultancy	-		
Salaries	19,615		
Pension	415		
Staff Training	-		
Travel	6,429		
Telephone & Internet	-		
Postage, Freight & Courier	80		
Printing & Stationery	138		
IT Software and Consumables	1,300		
Audit & Accountancy fees	1,361		
Professional Fees	210		
Insurance	711		
Subscriptions	85		
Donations	-		
Sundry	-		
Bank Fees	93		
Foreign Exchange	<u>87</u>		
		<u>53,085</u>	
Total Expenditure			61,256

Excess of Income over Expenditure	10,640
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Restricted Reserves	974
Unrestricted Reserves	38,686

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

Signature: _____ Name: _____

Date of Approval: _____

Pompe Support Network - Charity Number 1186383
YE 31Mar24 compared with YE 31Mar23

Charity No. 1186383

Income:		YE 31Mar24		YE 31Mar23 restated	
		£	£	£	£
Donations			8,780		5,945
Donations in Kind			22,500		35,350
Grants					
Restricted		18,000		26,355	
Unrestricted		<u>22,616</u>		<u>24,625</u>	
			<u>40,616</u>		<u>50,980</u>
Total Income			71,896		92,276

Expenditure:					
		£	£	£	£
Direct Expenses:					
Projects		6,956		4,368	
Public Speakers		-		-	
Awareness & Collaborative Meetings		-		-	
IT Consulting & Website Development		-		430	
Other Direct Expenses		1,214		1,375	
Fundraising		<u>-</u>		<u>-</u>	
			8,170		6,173
Administrative Expenses:					
Advertising & Marketing		62		309	
Management/Strategic Support		22,500		34,000	
Consultancy		-		1,200	
Salaries		19,615		24,000	
Pension		415		533	
Staff Training		-		-	
Travel		6,429		4,855	
Telephone & Internet		-		-	
Postage, Freight & Courier		80		-	
Printing & Stationery		138		63	
IT Software and Consumables		1,300		840	
Audit & Accountancy fees		1,361		2,321	
Professional Fees		210		-	
Insurance		711		-	
Subscriptions		85		252	
Donations		-		-	
Sundry		-		-	
Bank Fees		93		20	
Foreign Exchange		<u>87</u>		<u>-</u>	<u>61</u>
			<u>53,085</u>		<u>68,333</u>
Total Expenditure			61,256		74,506

Excess of Income over Expenditure	10,640	17,770
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Restricted Reserves	974	1,000
Unrestricted Reserves	38,686	16,519

Pompe Support Network - year ending 31 March 2024

Assets and Liabilities

Charity No. 1186383

Assets					
				£	£
Fixed Assets					
	20-Jan-21	Ikonic Tecknology - HP ProBook	850		
	04-Feb-21	techINN - laptop	<u>1,029</u>		
				1,879	
Bank					
			Restricted	Unrestricted	
	GBP	33,361	974	32,387	
	Wise GBP	89	-	89	
	Wise EUR	672	-	672	
	Wise USD	3,806	-	3,806	
	Paypal	<u>1</u>	<u>-</u>	<u>1</u>	
			974	36,956	37,929
Total Assets					39,808

Liabilities					
				£	£
Wages Payable - Payroll					
				-	
PAYE Payable					
				-	2
Pensions Payable					
				<u>150</u>	
					149
Total Liabilities					149

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

Signature: 

Name: Allan D J Muir

Date of Approval: 23 January 2025



Section A

Independent Examiner's Report

Report to the trustees/
members of

Charity Name
Pompe Support Network

On accounts for the year
ended

31st March 2024

Charity no
(if any)

1186383

Set out on pages

(remember to include the page numbers of additional sheets)

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended 31/03/2024.

Responsibilities and
basis of report

As the charity trustees of the Trust, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ("the Act").

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent
examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention (other than that disclosed below *) in connection with the examination which gives me cause to believe that in, any material respect:

- accounting records were not kept in accordance with section 130 of the Act or
- the accounts do not accord with the accounting records

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in order to enable a proper understanding of the accounts to be reached.

* Please delete the words in the brackets if they do not apply.

Signed:

Paul O'Brien

Date:

14/01/2025

Name:

Paul O'Brien

Relevant professional
qualification(s) or body
(if any):

ICPA

Address:

34 King James Close

Fordham, Ely

CB7 5SA

Only complete if the examiner needs to highlight matters of concern (see CC32, Independent examination of charity accounts: directions and guidance for examiners).

Give here brief details of any items that the examiner wishes to disclose.