

# TRUSTEES' REPORT

FOR THE Period 1<sup>st</sup> April 2024 to 31<sup>st</sup> March 2025

The Trustees present their annual report together with the financial statements of the company for the period 1<sup>st</sup> April 2024 to 31<sup>st</sup> March 2025. 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

Our CEO, Mrs Hülya Apaydin, continues as our part-time CEO, contracted to work 20 hours per week. Hülya is our sole employee supported by trustees and works with a small number of volunteers to perform the work of the Pompe Support Network.

## Website

The Pompe Support Network website, [www.pompe.uk](http://www.pompe.uk) remains a highly valued resource containing a growing number of podcasts, videos and research articles. 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.

## Social care and mental health counselling

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. and also through Rareminds, which is a rare disease charity specialist Mental Health Provider solely dedicated to the needs of people living with rare, genetic and undiagnosed conditions.

## Publications

We continue to develop and support publications for the Pompe disease community. Leo's Second Book is a children's book written and illustrated by Kara Dobbs (Price), Leo's mother. This is the second book Kara has written about Leo's life with Pompe. In this book Kara touches base on Enzyme Replacement Therapy (ERT) infusions in a fun way. We sponsored the first book called *Leo and the Floppy Sloth* and arranged its publication. The book was well received by the community.

## Pompe Patient Treatment Guidelines

Pompe Patient Guidelines and Patient Appointment Sheets are being developed by Pompe Support Network, at the request of an NHS specialist consultant. They will help to inform patients on several current treatment options and to enable patients to be part of shared-decision making with their clinicians.

## Patient Engagement

PSN have been engaging with the community by offering face-to-face meetings, video chats, and phone calls. The community welcome opportunities to talk to someone who can understand the needs and challenges of the condition. We will continue meeting patients and caregivers to better understand and support the need.

## 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 substantial donations-in-kind from trustees and volunteers.

#### Networking and collaborative working

Allan Muir is a founder member of the UK LSD Collaborative, a 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.

Hülya Apaydin continued to represent the PSN as a board member of the International Pompe Association (IPA).

#### Conferences and Meetings

An conference organised jointly by the AMDA (USA Pompe organisation) and the International Pome Association (IPA). It was held in San Antonio from 30 April to 5 May 2024. For the first time the conference was virtual as well as in person. Allan Muir, Kevin Annesty and Hülya Apaydin attended the conference in person from PSN

The conference was well attended by Pompe patients, family members, scientists, healthcare specialists and the industry. There were presentations on new developments in gene therapy. There was an emphasis on the holistic approach of Pompe treatment. Diet and exercise play an important role in the management of the condition. There were some presentations on Ketogenic diets and how they may be beneficial to people living with Pompe disease.

#### LSD Collaborative Meetings

There were a number of important meetings with the LSD Collaborative member organizations and LSD specialist centres. The meetings aim to explore changes and updates to the clinical services and guidelines with the clinical teams and LSD Collaborative members. Allan Muir and Hulya Apaydin attended all meetings. The meetings were particularly beneficial for the CEO to familiarise herself with the medical teams and their priorities.

#### Pompe Disease Advisory Focus Group meetings – University of York

The PSN helped to recruited patients and care givers with lived experience of Late-onset Pompe disease as an advisory group for a research team at the University of York. The project aimed to review and evaluate treatments for late-onset Pompe disease (LOPD) to determine the most effective and cost-effective treatment options.

The advisory focus group was comprised of clinical experts, people with lived experience of LOPD including both patients and care givers, as well as third-sector organisations that advocate for and support them.

PSN recruited six Pompe patients for the focus group. Hulya Apaydin, Allan Muir and Kevin Annesley from the PSN were present at all three meetings.

The project was developed following the NICE appraisal of “Cipaglucosidase alfa with miglustat” for treating LOPD – which involved members of the research team at York.

The NICE appraisal raised important questions about how decisions were being framed, given the history of provision for LOPD, that could potentially prevent effective treatments for LOPD from being made available to patients and also skew decisions about how much the NHS should pay for them.

The project was not aimed at unpicking the existing NICE guidance but was intended to be forward-looking, as NICE's willingness to recommend new technologies such as gene therapies in future will depend on the costs and clinical effectiveness of ERTs.

### Royal Free London NHS Foundation Trust

We were contacted by Dr Hatim Yusufali Ebrahim, PhD level laboratory scientist (specialised in molecular genetics). The chief scientific officer (CSO) in conjunction with NIHR and devices for dignity MedTech innovation at Sheffield University has awarded a one-year innovation fellowship to work on a project 'inequalities in routes to metabolic and genetic diagnosis in rare lysosomal storage disorders'.

They ran a short online survey and form a Focus group consist of 5-7 people.

They are examining the factors associated with prolonged diagnostic odyssey in patients with LSDs. The pathway commencing from the time of first referral, to ordering of various tests required to make a diagnosis (enzyme, biomarker, and genetic testing), to obtaining a final confirmatory diagnosis will be examined to identify the slowest steps in the process. This project will aim to deliver recommendations aligning with the government and the NHS vision to help patients get a faster diagnosis and improve their outcomes with timely initiation of licenced disease modifying treatments that slow progression of their conditions. They hope to learn more about the problems and experiences of patients living with Pompe disease and would like to engage with patients to gain insights of the problems they faced with their diagnostic odyssey. Through this patient and public involvement engagement (PPIE) it is hoped that patients with Pompe disease will be represented to help identify their unmet needs, determine their visions for improvement of services relating to their condition and help in co-formulating workable solutions to help achieve a faster diagnosis.

### 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 represented the European Pompe community at several Screen4Care meetings and events. Screen4Care is a European project to improve diagnosis and management of rare diseases.

### 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 has cash resources and has no requirement for external funding. At the date of signing the accounts the unrestricted reserve stands at £63,900. 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 22<sup>nd</sup> 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	
Wayne Belfitt	Trustee	
Malcolm Knightly	Trustee	
Luke Fraser	Trustee	Since 29th April 2025

### 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

26<sup>th</sup> January 2026

And signed on their behalf

A handwritten signature in blue ink, appearing to read 'Allan Muir', followed by a horizontal line.

Allan Muir  
Chair of Trustees



Charity registration number: 1186383

**Pompe Support Network**

Financial Statements  
for the Year Ended 31 March 2025

# Pompe Support Network

## Reference and Administrative Details

<b>Charity name:</b>	Pompe Support Network
<b>Charity registration number:</b>	1186383
<b>Principal Office:</b>	43a North Lane Buriton Petersfield GU21 5RS
<b>Trustees:</b>	Allan David John Muir (Chair) Luke David Fraser Malcolm Knightley Wayne Belfitt Kevin William Annesley Barbara Jane Muir Dr Kevin John O'Donnell

# Pompe Support Network

## Independent Examiners Report

I report on the accounts of Pompe Support Network for the year ended 31 March 2025.

### **Respective responsibilities of Trustees and examiner**

The Charity's trustees are responsible for the preparation of the accounts. The charity's trustees consider that an audit is not required for this year under section 144(2) of the Charities Act 2011 (the 2011 Act) and that an independent examination is needed.

It is my responsibility to:

- \* examine the accounts under section 145 of the 2011 Act
- \* to follow the procedures laid down in the general Directions given by the commission under section 145(5)(b) of the 2011 Act
- \* to 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 charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, 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 given as to whether the accounts present a 'true and fair view' and the report is limited to consequently no opinion is given as to whether the accounts present a 'true and fair view' and the report is limited to those matters set out in the next statement.

### **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 130 of the 2011 Act and
  - \* to prepare accounts which accord with the accounting records and comply with the accounting requirements of the 2011 Acthave not been met or
- 2) to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached

*Paul O'Brien*

Name: Paul O'Brien (ICPA) - Dragonfly (Accounting & Financial Management) Ltd  
Address: 34 King James Close, Fordham, Ely, CB7 5ZH

# Pompe Support Network

## Statement of Financial Activities for the year ended 31 March 2025

	Unrestricted Funds £	Total 2025 £	Total 2024 £
<b><u>Incoming resources:</u></b>			
Donations	1,572	1,572	8,780
Donations in Kind	12,100	12,100	22,500
Grants received: Unrestricted	44,808	44,808	40,616
Grants received: Restricted	35,000		
Other income	60	60	-
<b>Total Incoming resources</b>	<b>93,540</b>	<b>58,540</b>	<b>71,896</b>
<b><u>Resources expended</u></b>			
<b>Direct Expenses</b>			
Projects	-	-	6,956
Other Direct Expenses	16,426	16,426	1,214
	<b>16,426</b>	<b>16,426</b>	<b>8,170</b>
<b>Administrative Expenses</b>			
Advertising & Marketing	-	-	62
Management / Strategic Support	12,100	12,100	22,500
Salaries	30,904	30,904	19,615
Pension	1,428	1,428	415
Travel	101	101	6,429
Postage	33	33	80
Printing & stationary	-	-	138
IT Software & consumables	1,284	1,284	1,300
Audit & Accountancy	4,365	4,365	1,361
Professional fees	-	-	210
Insurance	387	387	711
Subscriptions	118	118	85
Bank fees	12	12	93
Foreign exchange	98	98	87
Depreciaton	1,047	1,047	-
Sundries	21	21	-
	<b>51,900</b>	<b>51,900</b>	<b>53,085</b>
<b>Total Expenditure</b>	<b>68,326</b>	<b>68,326</b>	<b>61,256</b>
<b>Net Income/(Expenditure) for the year</b>	<b>25,214</b>	<b>(9,786)</b>	<b>10,640</b>
<b><u>Reconciliation of funds</u></b>			
Total funds b/f: Restricted	974	39,660	29,020
Total funds b/f: Unrestricted	38,686		
<b>Total funds carried forward</b>	<b>64,874</b>	<b>29,874</b>	<b>39,660</b>



# Pompe Support Network

## Balance Sheet for the year ended 31 March 2025

	2025 £	2024 £
<b>FIXED ASSETS</b>		
Equipment	832	1,879
<b>CURRENT ASSETS</b>		
Cash at bank and in hand	59,627	37,929
Other Debtors	4,711	-
	<u>64,337</u>	<u>37,929</u>
<b>CREDITORS:</b> amounts falling due within one year	<u>(295)</u>	<u>(149)</u>
<b>NET CURRENT ASSETS</b>	<u>64,042</u>	<u>37,929</u>
<b>NET ASSETS</b>	<u>64,874</u>	<u>39,660</u>
<b>FUNDS</b>		
Restricted funds	974	974
Unrestricted funds	63,900	38,686
<b>TOTAL FUNDS</b>	<u>64,874</u>	<u>39,660</u>

The financial statements were approved and authorised for issue by the Trustees  
and signed on their behalf by:



.....  
Allan Muir (Chair)  
Trustee

Date 26th January 2026  
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