

POMPE SUPPORT NETWORK

England & Wales · Charity number 1186383

Details

Other names	PSN
Status	Registered
Legal form	CIO
Registered	2019-11-15
Register	View on the Charity Commission register

Contact

Address	43a North Lane Buriton Petersfield GU31 5RS
Phone	01730231554
Email	hello@pompe.uk
Website	www.pompe.uk

Activities

Objects: 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

Activities: The Pompe Support Network is an organisation developed by the UK Pompe community in order to support others within the community. Together we: - Provide peer to peer support - Support research into medical and supportive care. - Provide information about promising medical developments. - Advocate for access to medical therapies or devices. - Share life experiences

Classification

- **How:** Makes Grants To Individuals, Makes Grants To Organisations, Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** Children/young People, Elderly/old People, People With Disabilities

Geography

- Northern Ireland
- Scotland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£93,540	£68,326	-	-
2024-03-31	£71,896	£61,256	-	-
2023-03-31	£92,276	£74,506	-	-
2022-03-31	£79,526	£118,709	-	-
2021-03-31	£93,292	£45,332	-	-

Trustees

Name	Role	Appointed
Allan David John Muir	Chair	2019-12-20
Barbara Jane Muir		2019-12-20
Dr Kevin John O'Donnell		2019-12-20
Kevin William Annesley		2020-01-25
Luke David Fraser		2025-05-01
Malcolm Knightley		2023-04-29
Wayne Belfitt		2022-10-15

Accounts

TRUSTEES' REPORT

FOR THE Period 1st April 2024 to 31st March 2025

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

26th 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

Charity name:	Pompe Support Network
Charity registration number:	1186383
Principal Office:	43a North Lane Buriton Petersfield GU21 5RS
Trustees:	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 £
<u>Incoming resources:</u>			
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	-
Total Incoming resources	93,540	58,540	71,896
<u>Resources expended</u>			
Direct Expenses			
Projects	-	-	6,956
Other Direct Expenses	16,426	16,426	1,214
	16,426	16,426	8,170
Administrative Expenses			
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	-
	51,900	51,900	53,085
Total Expenditure	68,326	68,326	61,256
Net Income/(Expenditure) for the year	25,214	(9,786)	10,640
<u>Reconciliation of funds</u>			
Total funds b/f: Restricted	974	39,660	29,020
Total funds b/f: Unrestricted	38,686		
Total funds carried forward	64,874	29,874	39,660

Pompe Support Network

Balance Sheet for the year ended 31 March 2025

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

Accounts

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
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c. Activities undertaken to achieve objectives

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Achievements and performance

a. Review of activities

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- Provide accessible and clear supply of information for all stakeholders
- Provide timely information relating to new medical interventions
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- Provide independent advice relating to clinical studies for Pompe disease
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- 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.

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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 Hülya 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
--	---------------

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

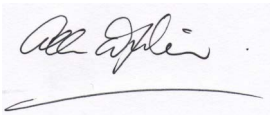
Charity No. 1186383

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>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.

Accounts

TRUSTEES' REPORT

FOR THE Period 1st April 2022 to 31st March 2023

The Trustees present their annual report together with the financial statements of the company for the period 1st April 2022 to 31st March 2023. 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 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 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 who works at Psychology Partners.

Webinars, Video and Audio projects

During this period, we recorded and published further podcasts for our Pompe Voices collection that are now available in our online library. One video was recorded to show how Virtual Reality can help those with health conditions, including Pompe Disease.

Publications

Considerable effort has been spent to develop a book created by the Pompe Community for the Pompe Community. It is a collection of activities that people undertake and shows how individuals are enjoying life. This inspiring book will be published later in 2023 and was created thanks to a grant from the National Lottery.

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.

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, 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.

During this period Allan Muir was also vice-chair of the International Pompe Association (IPA).

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, Hulya Apaydin and Alex Jones attended the WORLD Symposium in Orlando where the charity was allocated a booth where we shared our literature and discussed our work with many delegates from around the world. Alex Jones produced a short video to showcase the importance of patient group representation at international events, such as this.

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 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 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

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 continuing 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 £16,519. 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	
Dr Kevin John O'Donnell	Trustee	
Mrs Hülya Apaydin	Trustee	
Wayne Belfitt	Trustee	Appointed on 15 October 2022

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:

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- 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 2024

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 2023

Prepared by:
Miss S - Accounting for Purpose CIC



Pompe Support Network - year ending 31 March 2023
Income and Expenditure

Charity No. 1186383

Income:			
	£	£	£
Donations		5,945	
Donations in Kind		35,350	
Grants			
Restricted	26,355		
Unrestricted	<u>24,625</u>		
		<u>50,980</u>	
Total Income			92,276

Expenditure:			
	£	£	£
Direct Expenses:			
Projects	4,368		
Public Speakers	-		
Awareness & Collaborative Meetings	-		
IT Consulting & Website Development	430		
Other Direct Expenses	1,375		
Fundraising	<u>-</u>		
		6,173	
Administrative Expenses:			
Advertising & Marketing	309		
Management/Strategic Support	34,000		
Consultancy	1,200		
Salaries	24,000		
Pension	533		
Staff Training	-		
Travel	4,855		
Telephone & Internet	-		
Postage, Freight & Courier	-		
Printing & Stationery	63		
IT Software and Consumables	840		
Audit & Accountancy fees	2,321		
Professional Fees	-		
Subscriptions	252		
Donations	-		
Sundry	-		
Bank Fees	20		
Foreign Exchange	<u>- 61</u>		
		<u>68,333</u>	
Total Expenditure			74,506

Excess of Income over Expenditure	17,770
--	---------------

Restricted Reserves	10,000
Unrestricted Reserves	16,519

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

Signature: _____ Name: _____

Date of Approval: _____

Pompe Support Network - Charity Number 1186383
YE 31Mar23 compared with YE 31Mar22

Charity No. 1186383

Income:		YE 31Mar23		YE 31Mar22 restated	
		£	£	£	£
Donations			5,945		9,758
Donations in Kind			35,350		57,550
Grants					
	Restricted	26,355		9,001	
	Unrestricted	<u>24,625</u>		<u>3,535</u>	
			<u>50,980</u>		<u>12,536</u>
Total Income			92,276		79,844

Expenditure:					
		£	£		£
Direct Expenses:					
Projects		4,368		55,071	
Public Speakers		-		-	
Awareness & Collaborative Meetings		-		-	
IT Consulting & Website Development		430		500	
Other Direct Expenses		1,375		-	
Fundraising		<u>-</u>		<u>-</u>	
			6,173		55,571
Administrative Expenses:					
Advertising & Marketing		309		-	
Management/Strategic Support		34,000		34,000	
Consultancy		1,200		6,612	
Salaries		24,000		16,000	
Pension		533		266	
Staff Training		-		-	
Travel		4,855		501	
Telephone & Internet		-		-	
Postage, Freight & Courier		-		14	
Printing & Stationery		63		-	
IT Software and Consumables		840		679	
Audit & Accountancy fees		2,321		2,354	
Professional Fees		-		520	
Subscriptions		252		164	
Donations		-		-	
Sundry		-		-	
Bank Fees		20		33	
Foreign Exchange		<u>- 61</u>		<u>- 265</u>	
			<u>68,333</u>		<u>60,877.06</u>
Total Expenditure			74,506		116,448

Excess of Income over Expenditure	17,770	- 36,604
--	---------------	-----------------

Restricted Reserves	10,000	-
Unrestricted Reserves	16,519	10,792

Prior Year Adjustment

The Reserves at 31 March 2022 have been adjusted by £2,044 to reflect a true and fair view of the Charity's closing position as at 31 March 2023.

Pompe Support Network - year ending 31 March 2023

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	23,136	10,000	13,136
	Wise GBP	103		103
	Wise EUR	693		693
	Wise USD	-	-	-
	Paypal	<u>811</u>	<u>-</u>	<u>811</u>
			10,000	14,742
				24,742
Total Assets				26,621

Liabilities				
			£	£
Wages Payable - Payroll				
			-	
PAYE Payable				
			-	2
Pensions Payable				
			<u>104</u>	
				102
Total Liabilities				102

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

Signature: _____

Name: _____

Date of Approval: _____

Pompe Support Network
(back page)

**POMPEY SUPPORT NETWORK
INDEPENDENT EXAMINER'S REPORT ON THE ACCOUNTS
FOR THE YEAR ENDED 31ST MARCH 2023**

Report to the trustees/ members of Pompey Support Network on the accounts for the year ended 31st March 2023.

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 of the Charities Act 2011 (the Charities Act) and that an independent examination is needed.

It is my responsibility to:

- examine the accounts under section 145 of the 2011 Charities Act,
- to follow the procedures laid down in the general Directions given by the Charity Commission (under section 145(5)(b) of the Charities Act, and
- to state whether particular matters have come to my attention.

Basis of independent examiner's statement

My examination was carried out in accordance with 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 the trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit, and consequently no opinion is given as to whether the accounts present a 'true and fair' view and the report is limited to those matters set out in the statement below.

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 Charities Act; and
- to prepare accounts which accord with the accounting records and comply with the accounting requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination

have 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.

Donna Leppitt
Independent Examiners Ltd
Unit 2
The Broadridge Business Centre
Delling Lane
Bosham
PO18 8NF



Date: 30th April 2024

Accounts

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
--	--------------------

Fixed Assets	1,878.97
---------------------	-----------------

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.

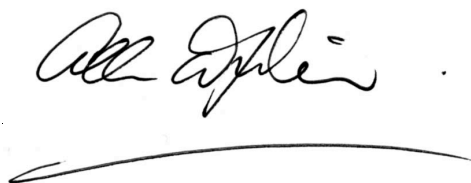
1186383

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
(back page)

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		
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IT Software and Consumables	848.42		
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		<u>63,137.92</u>	
Total Expenditure			118,708.76

Excess of Income over Expenditure	- 39,183.03
--	--------------------

Fixed Assets	1,878.97
---------------------	-----------------

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
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	Restricted	9,001.03		29,069.22	
	Unrestricted	<u>3,534.87</u>		<u>32,821.77</u>	
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Total Income			79,525.73		83,292.02
Expenditure:					
		£	£		£
Direct Expenses:					
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	Public Speakers	-		4,000	
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	Salaries	18,000.00		-	
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	Travel	548.70		788.32	
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	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.

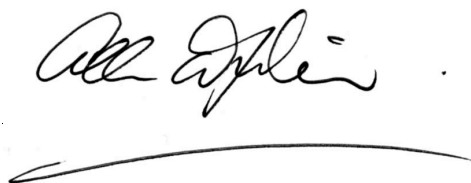
1186383

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				£	£
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	Paypal	<u>642.58</u>	-	<u>642.58</u>	
			-	8,913.29	8,913.29
Total Assets					10,792.26

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				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
(back page)

Accounts

TRUSTEES' REPORT

FOR THE Period 15th November 2019 to 31st MARCH 2021

The Trustees present their annual report together with the financial statements of the company for the period 15th November 2019 to 31 March 2021. 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, 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 been very successful in making progress in all areas, some examples are listed below.

Website

Our website was created and published in November 2019 and in May 2020 we recruited a communications manager to oversee the website content, maintenance, and the management of our social media channels and also the production and dissemination of regular newsletters to our subscribers.

Webinars, Video and Audio projects

From the outset, it was decided that Pompe Support Network would favour online webinars over annual conferences. The format is much more accessible for a community spread so widely geographically, and with accessibility issues. For that reason, we created the Zoom into Pompe (ZIP) series of webinars that feature a professional speaker and allow plenty of time for participants to ask questions, followed by general discussion. The presentations are published online within our Video library. We held 6 such meetings in the period to March 2021 and the videos are available through our website or our YouTube channel.

Through the Pompe Voices project we have created a number of podcasts, recorded with members of the Pompe community. Each podcast features a member of the Pompe community in conversation with, for example, their partner, sibling, friend, or carer, discussing the good, bad, and often amusing stories of living with Pompe Disease.

During this period, we also planned the production of an episodic film about Pompe disease. This will be filmed later in 2019 and will comprise five episodes showing the lives of people living with Pompe disease. They will cover a wide age range and different aspects of life; but each will concentrate on the abilities of people, rather than their disability.

Fundraising

We have created accounts on several platforms to enable donations to be received directly. These include Amazon Smile, Give as you Live, VirginMoneyGiving, Facebook Donations, PayPal Donate, eBay for Charity.

Five places we bought for the RideLondon cycling event, however the event was cancelled and refunded due to the Covid-19 pandemic.

Grant Applications

We have been very successful with our grant applications to the National Lottery Community Fund and several biotechnology companies including Sanofi-Genzyme, Amicus Therapeutics, Audentes Therapeutics, AskBio, Spark Therapeutics, AvroBio. Overall, the grant income exceeded our initial forecasts leaving the PSN in a very comfortable financial position as we anticipate major expenses and uncertainties for the planned film production.

Networking and collaborative working

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

Allan Muir was invited to speak at a meeting of the European Pompe Consortium (EPOC) for a meeting to discuss the diagnosis, care and management of Pompe disease.

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, Avalglucosidase Alpha, is under development by Sanofi-Genzyme. Allan Muir submitted the Scoping forms and attended the Scoping committee meeting on behalf of the Pompe community.

Neonatal Screening

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.

Research

Pompe support Network has supported research through companies investigating the quality of life of people living with Pompe disease, their expectations and experience of current and future treatments. Allan Muir is a co-author of papers resulting from this research and will present a poster at the World Muscle Society conference, later in 2019.

The Impact of Covid 19

Coronavirus has had an immense impact on everyone's lives and all charities have been affected.

A Covid-19 website page was set up to help members find the latest reliable information on the pandemic.

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 £35,210.68. 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 ".

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

27th January 2022

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 period 15 November 2019 to 31 March 2021

Pompe Support Network - period 19 November 2019 to 31 March 2021
Independent Examiner's Report to the Trustees of Pompe Support Network

Period End 31 March 2021
Charity No. 1186383

I report to the trustees on my examination of the accounts of the above charity for the period ended 31 March 2021 which are set out on pages 3 to 4.

Responsibilities and basis of report

As the charity's trustees, 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 Charity's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed all 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 in connection with the examination which gives me cause to believe that in, any material respect:

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

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

Signed:



Date:

24-Jan-22

Name:

Miss Fiona M Sanderson BA(Hons) ACMA CGMA MICB
Miss S Business Support Ltd
Office 14, Steel House
4300 Parkway
Whiteley
PO15 6FP

Pompe Support Network - period 19 November 2019 to 31 March 2021
Income and Expenditure

Charity No. 1186383

Income:			
	£	£	£
Donations		5,901.03	
Donations in Kind		25,500.00	
Grants			
Restricted	29,069.22		
Unrestricted	<u>32,821.77</u>		
		<u>61,890.99</u>	
Total Income			93,292.02

Expenditure:			
	£	£	£
Direct Expenses:			
Projects	765.65		
Public Speakers	4,000.00		
Awareness & Collaborative Meetings	3,600.00		
IT Consulting & Website Development	16,830.00		
Fundraising	<u>502.26</u>		
		25,697.91	
Administrative Expenses:			
Advertising & Marketing	1,764.77		
Management/Strategic Support	12,800.00		
Staff Training	322.52		
Travel	788.32		
Telephone & Internet	45.00		
Postage, Freight & Courier	35.42		
Printing & Stationery	92.25		
IT Software and Consumables	2,950.21		
Audit & Accountancy fees	45.00		
Professional Fees	200.00		
Subscriptions	375.55		
Sundry	58.00		
Bank Fees	141.55		
Foreign Exchange	<u>15.17</u>		
		<u>19,633.76</u>	
Total Expenditure			45,331.67

Excess of Income over Expenditure	47,960.35
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Fixed Assets	1,878.97
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Restricted Reserves	10,870.70
Unrestricted Reserves	35,210.68

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

Signature:



Name:

Mr Allan D J Muir

Date of Approval:

27th January 2022

Pompe Support Network - period 19 November 2019 to 31 March 2021

Assets and Liabilities

Charity No. 1186383

Assets					
				£	£
Assets retained for the charity's own use					
	Ikonic Tecknology - HP ProBook	849.99			
	techINN - laptop	<u>1028.98</u>			
				1,878.97	
Bank					
			Restricted	Unrestricted	
	GBP	45,670.79	10,870.70	34,800.09	
	Wise US Dollar	13.97	-	13.97	
	Paypal	<u>396.62</u>	<u>-</u>	<u>396.62</u>	
			10,870.70	35,210.68	46,081.38
Total Assets					47,960.35

Liabilities					
				£	£
None					
Total Liabilities					-

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Signature:

Name:

Mr Allan D J Muir

Date of Approval:

27th January 2022

Pompe Support Network
(back page)

Charity No. 1186383

43a North Lane
Buriton
Petersfield
GU21 5RS

Pompe Support Network

for the period 15 November 2019 to 31 March 2021

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Audit & Accountancy fees	45.00		
Professional Fees	200.00		
Subscriptions	375.55		
Sundry	58.00		
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Foreign Exchange	<u>15.17</u>		
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Total Expenditure			45,331.67

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Name:

Mr Allan D J Muir

Date of Approval:

27th January 2022

Pompe Support Network - period 19 November 2019 to 31 March 2021

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Total Liabilities					-

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Pompe Support Network
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