

PULMONARY FIBROSIS NI

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT)

FOR THE YEAR ENDED 29 FEBRUARY 2024

The trustees present their annual report and financial statements for the year ended 29 February 2024.

The financial statements have been prepared in accordance with the accounting policies set out in note 1 to the financial statements and comply with the charity's [governing document], the Companies Act 2006 and "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)" (effective 1 January 2019).

Constitution & Purpose

Pulmonary Fibrosis NI (PFNI) is a charity governed by a constitution & recognised as a Private Limited Company by guarantee without share capital use of 'Limited' by Companies House, incorporated 8 February 2022; Company No. NI685604, Charity Number 109094.

It is managed by the trustees. Trustees are appointed by invitation & agreement of the Trustees at the AGM or an Extraordinary General Meeting. Trustees may hold office for a maximum of 2 years before re-appointment is required unless they resign or are removed from office by a resolution of the other trustees at the AGM or an Extraordinary General Meeting.

PFNI primarily seeks to benefit the Northern Ireland community through its activities which aim to provide support and relief for people living with Pulmonary Fibrosis and other Interstitial Lung Diseases in Northern Ireland and to advance education about Pulmonary Fibrosis and other Interstitial Lung Diseases.

Public Benefit

The public benefits that flow from this purpose are to:

- a. foster an atmosphere of mutual support and encouragement among people suffering from Pulmonary Fibrosis and other Interstitial Lung Diseases (PF) and their carers, family and friends;
- a. raise awareness for the benefit of the public about the effects of Pulmonary Fibrosis and other Interstitial Lung Diseases and methods of management of such disease;
- a. raise awareness for the benefit of the public about the effects of Pulmonary Fibrosis and other Interstitial Lung Diseases and methods of management of such disease;
- a. promote and raise awareness of the Organ Donor Register for the benefit of the public.

The beneficiaries of this purpose are people living in Northern Ireland who have been diagnosed with pulmonary fibrosis and other interstitial lung diseases, their families, friends, colleagues, and the general public at large.

The direct benefits flowing from this purpose include improved mental health and reduced levels of stress and anxiety experienced by our beneficiaries & an increase in their knowledge of how to live well with their condition. These benefits are evidenced through feedback from beneficiaries at appropriate intervals. A private benefit flowing from this purpose is the experience and knowledge members receive. However, this is incidental and necessary as it is essential to ensure the benefit is provided to our beneficiaries. A private benefit is also gained by suppliers who receive payments for goods and services provided. The benefit is incidental and necessary to ensure that benefit is provided to our beneficiaries. Any expenses paid to Trustees is reimbursement for expenses necessarily incurred in pursuit of the aims of the charity or of purchases made on behalf of the charity.

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TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) **FOR THE YEAR ENDED 29 FEBRUARY 2024**

The purposes of our charity may lead to the following risks:

- a. Trips and falls when beneficiaries are using:
 - i. Puffin Lodge (our respite caravan). This facility is unsuitable for people who use wheelchairs or mobility scooters or who are unable to negotiate stairs. Site limitations are highlighted to applicants and mobility is assessed during the application process.
 - i. Events venues. Venues etc are assessed and chosen to ensure that the majority of our beneficiaries can attend & use safely and comfortably.
- b. Some beneficiaries require oxygen (O2) which can be delivered to Puffin Lodge by BOC Ltd. The risks to beneficiaries associated with O2 include:
 - i. non-delivery by BOC (note: timely ordering of O2 for delivery to & use at Puffin Lodge is the responsibility of the beneficiary & they will contact BOC if this occurs);
 - i. The equipment required to meet the O2 requirements of the beneficiary would generate noise levels that are acceptable to other site users.

Oxygen needs are discussed with the applicant and assessed during the application process. Unfortunately Puffin Lodge, due to its location and construction, cannot facilitate the needs of all our beneficiaries.

O2 needs of beneficiaries are considered when organising events to ensure, as far as reasonably practicable, that the majority of beneficiaries can attend.

The potential of any such harm or risk arising is outweighed by the benefit provided to the public.

The trustees have paid due regard to guidance issued by the Charity Commission in deciding what activities the charity should undertake.

PULMONARY FIBROSIS NI

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

FOR THE YEAR ENDED 29 FEBRUARY 2024

Review of Public Benefit Activities in 2023/24

PFNI continued to develop their activities to reach and serve people with Pulmonary Fibrosis (PF), their carers and families, and increase awareness of PF within the community at large.

Puffin Lodge, our respite static caravan in Ballycastle was officially opened on 30 March 2023 by Robin Swann, MLA and former Health Minister and Pat Gorman, ILD Specialist Nurse at Antrim Area Hospital & 2022 Patients Choice Nurse of the Year. Throughout the year (Mar-Nov) Puffin Lodge was well used by families to have a much needed break from home; it also hosted fundraising coffee mornings which welcomed other caravan owners and the general public and opened conversations about the work of PFNI.

Further public benefit activities included:

- a. Production of a comprehensive information pack that clinicians give to their patients on diagnosis or can be requested from PFNI directly. These were developed in collaboration with specialist PF clinicians.
- b. Weekly Zoom meeting were held for PF patients & monthly meeting for carers. Speakers from the Health Boards & NI Hospice were invited to talk to attendees about issues relevant to them including dealing with fatigue, nutrition, dealing with stress & anxiety, and the ever popular relaxation taster session.
- c. The number of Ambassadors increased during the year & an Ambassador Co-ordinator (Trustee) appointed. Ambassadors liaise with and assist beneficiaries in their local area
- d. Purchase of hand-held fans for distribution to PF patients by clinicians.

Education

We attended numerous events where we were able to provide information to the public about Pulmonary Fibrosis and PFNI. These ranged from fundraising events to specialist conferences.

Our website is extensive and regularly updated. We aim to support and supplement information provided by clinicians about PF and ensure that all information provided is accurate and current by liaising with medical professionals.

Financial review

Annual Income

During the year the Charity generated incoming resources of £279,528.

All incomes were derived from personal or business donations and fundraising activities by our beneficiaries and supporters.

Annual Expenditure

Financially 2023/24 was a satisfactory year for PFNI. Apart from costs associated with administration of the charity all expenditure was in the furtherance of the aims of the charity. All volunteers are entitled to receive out-of-pocket expenses. All volunteers are entitled to receive travel expenses for journeys on official business which are paid at a standard rate accepted by HMRC as giving no personal gain to the recipient.

Outgoing resources were £30,145 leaving net incoming resources of £249,383 for the year to 31 March 2023.

Charity reserves should provide the organisation with adequate financial stability and the means for it to meet its charitable objectives for the foreseeable future.

The Trustees retain funds in the Charity to finance the ongoing running costs of the charity and to provide funds at short notice to finance the objectives of the charity.

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TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 29 FEBRUARY 2024

Plans for future periods

The Trustees of PFNI plan to:

- a. Purchase a property that is suitable for use all-year-round by even more PF patients, their carers & families, that is disability friendly, and is located in an area that is peaceful and relaxing for users.
- e. Encourage the use of both properties by those living with PF to enjoy so rest and relaxation.
- f. To continue to build strong relationships with medical professionals.
- g. To continue to build relationships with local, national and international communities, businesses & charities to improve and increase awareness & knowledge of PF & PFNI.
- h. To provide events and activities to benefit the knowledge, mental health and wellbeing of our beneficiaries.
- i. To identify areas where we can provide support for family members of PF patients, including children.

Structure, governance and management

The trustees, who are also the directors for the purpose of company law, and who served during the year and up to the date of signature of the financial statements were:

T J McMillan

J M Byrne

M U McMillan

P M Gorman

I Simpson

Dr. N Chaudhuri

(Appointed 16 June 2023)

C J Donohoe

(Appointed 16 June 2023)

The trustees' report was approved by the Board of Trustees.



Judith M Byrne (Nov 30, 2024 13:44 GMT)

J M Byrne

Trustee

28 November 2024