ACTION FOR PULMONARY FIBROSIS

Report from Trustees and Financial Statement
for the year to 30 June 2015

Our vision:

A world in which everyone living with pulmonary fibrosis has a better future

Charity registration number: 1152399

Trustees' Report
for year ended 30 June 2015

Action for Pulmonary Fibrosis (APF) is working to improve the experience of patients suffering from idiopathic pulmonary fibrosis (IPF) and other forms of pulmonary fibrosis. It aims to ensure that all patients, wherever they live in the UK, receive the best treatment and care possible in accordance with nationally approved guidelines. In addition APF aims to extend the range of additional support to patients and their close family members so that they can share their experiences and benefit from learning more about the disease and how it can best be managed.

Idiopathic Pulmonary Fibrosis (IPF) is a devastating, terminal lung condition affecting at least 15,000 adults in the UK. Numbers are increasing, there is no cure and it has no known cause. Each year 5,000 people die from the disease and the average life expectancy after diagnosis is around three years. The disease causes scar tissue to build up in the lungs, ultimately preventing the lungs from transferring oxygen into the body. This leads to shortness of breath that worsens as the disease progresses, and ultimately ends in respiratory failure. Although the outcomes are worse than for some cancers IPF receives very little research funding and much more is needed to enable our world leading scientists to undertake significant research.

In the two years since its inception, Action for Pulmonary Fibrosis has established itself firmly as a dedicated and experienced organisation, widely recognised by patients and family members as one that represents them and works on their behalf. APF representatives all have personal experience of the disease.

The trustees are pleased to present their report with the financial statements for the year ended 30 June 2015.

Charity Structure and Management

Action for Pulmonary Fibrosis was registered with the Charity Commission as a Charitable Incorporated Organisation (CIO) in June 2013

Charity Registration Number 1152399

Registered address:	Beechcroft, Westley, Bury St Edmunds, Suffolk, IP33 3TR
Telephone:	07554 803293
Email:	info@actionpulmonaryfibrosis.org
Website:	www.actionpulmonaryfibrosis.org

The governing document of the Charity is a Constitution approved by the trustees on 28 May 2013.

The trustees meet formally at quarterly meetings during the year to assess the charity's progress, to formulate general policy and strategy and to plan the activities for the coming period. They are ultimately responsible for the day-to-day management of the charity, including the making, enforcing and amending of rules, and the authority for all expenditure. The current operational management of the charity is conducted by the trustees. In addition to formal meetings, trustees liaise on an ongoing basis through online communication and informal meetings. All trustees give of their time freely and no trustee remuneration was paid in the year. Trustees are required to disclose all relevant interests and register them with the Charity Secretary and, in accordance with The Charity's policy, withdraw from decisions where a conflict of interest arises.

APF started the year with nine trustees, all of whom have direct experience of the disease. They include two patients, four family members and three medical specialists. An additional trustee has been appointed since the end of the financial year who is also the family member of a patient.

Trustees for the year to 30 June 2015:

Michael Bray (Chair)	
John F Morgan (Treasurer)	treasurer to 30.9.15
John R Morgan (Treasurer)	appointed trustee and treasurer on 1.10.15
Elizabeth Bray (Secretary)	
Wendy Dickinson	
Annette Duck	
Neil Hicks	
Karen Hughes	
Dr Gisli Jenkins	
Dr Helen Parfrey	

Appointment of new trustees

The board of trustees identify further skills required and seek to appoint new members to strengthen the board and where necessary to replace any member who decides not to seek re-appointment.

New appointments are considered and agreed by all trustees at a meeting of the board. New trustees are invited to attend a trustee meeting prior to appointment. Following appointment new trustees are inducted into the charity.

Risk Management

Responsibility for risk management lies with trustees and a risk register has been established. Risks have been identified and control systems have been established to manage risks.

Charity Objectives

The stated objectives of Action for Pulmonary Fibrosis are:

a) Advancing education and raising awareness of Pulmonary Fibrosis, the symptoms associated with it and encouraging earlier diagnosis of the condition.

b) Promoting research into the understanding, diagnosis, causes and treatments of pulmonary fibrosis through donations and grants to related research projects in order that the useful results of research are disseminated for public benefit.

c) Providing support to patients and families suffering from pulmonary fibrosis in any other way the trustees see fit.

Our Vision:

A world in which everyone living with pulmonary fibrosis has a better future.

Our Values:

- **Integrity** - APF will work with transparency and integrity in all that it does; putting the interests of patients and families first.
- **Collaboration** - The charity will work in a spirit of Partnership with other organisations, when it is appropriate and beneficial to do so, so that knowledge and expertise can be shared.
- **Support** - Give people living with IPF the best possible quality of life
- **Commitment** – Bring energy and resourcefulness to all activities

Achievements for the year

The Charity undertook activities relating to all three objectives during the year. The main activities were:

1 Supporting Patients

In addressing the aim to support patients and their families, APF has continued to engage in extending the number of patient and family support groups across the country. Although the number of groups has increased, from only 8 in 2013 to 27 in 2015 there are still large areas of the UK without a support group.

A project was undertaken by APF to assist the setting up of new support groups which resulted in seven new groups this year. The success of the groups depend on the initiative and enthusiasm of NHS respiratory staff or family members to establish the groups with advice, guidance and initial financial assistance from APF. Liaison is maintained with existing and new groups and trustees have visited most support groups to encourage them in their work and to promote the charity. This continues to be an important aspect of the charity's work and the success of the project has resulted in APF working with a further group of hospitals across the country to set up more new groups in the coming year. As the number of groups increases, patients and family members become more aware of the provision and benefits for those fortunate enough to be able to access a group and so the demand increases. Support groups are very important to patients and family members, providing an improved understanding of the disease and its management through contact with others in a similar position, which contributes to improvements in their own quality of life.

During the year APF supported, through a grant for refurbishment and equipment, the provision of four supportive care rooms for pulmonary fibrosis patients at Nottingham City Hospital. The rooms, which include ensuite facilities, are equipped with a second bed and facilities to enable a family member to stay overnight with the patient. The use of the rooms will be evaluated during the coming year and if successful it is intended to offer similar grants at other hospitals where the accommodation is available to provide improved facilities for pulmonary fibrosis patients.

APF contributed to a number of information events across the UK which were attended by patients and family members and which included presentations about the disease from medical experts, suggestions for improving quality of life and updates on current research.

2 Education and Awareness Raising

APF conducted a significant patient survey in the summer of 2015 which attracted responses from over 300 patients and 18 hospital trusts. It focused on IPF patients and the implementation of the NICE IPF Quality Standard which was published at the beginning of 2015. The survey resulted in a key report ***Working Together: Delivering a Better Future for IPF Patients***, which showed that there is considerable variation in the experience of patients across the country and in particular their access to pulmonary rehabilitation, oxygen therapy and to a specialist ILD nurse, all of which are identified as patient entitlements within the Quality Standard. This has given trustees evidence that is being presented to influencers and decision-makers to gain improvements in the quality of care for patients.

Our work in relation to education of health professionals continues to be an important aspect of the charity's work. Feedback from patients and family members often indicates that although their experience when referred to specialist staff is excellent, the interaction of patients with local medical professionals is often less satisfactory. Local health professionals see very few pulmonary fibrosis patients and often are unaware of their particular needs. It is encouraging that they are becoming more alert to the need to extend their knowledge.

With this in mind, APF has developed a training session for local and community nurses which has been successfully trialled and will be promoted further in the coming year. APF also contributes to training days for ILD specialist nurses, other health care professionals and researchers to help them to understand the disease from a patient's perspective. Opportunities are taken at relevant conferences both local and national to bring IPF to the attention of primary care practitioners to highlight the need for early diagnosis.

APF has continued to represent the patient community at national and European level which includes representing patients at national consultations on clinical guidelines, quality standards and new drug appraisals conducted by NICE and the Scottish Medicines Consortium (SMC). APF is also taking part in the development of a European Federation of IPF patient groups which has presented an IPF patient charter to the European Parliament.

3 Research

Although the UK benefits from having world leading researchers into IPF, the funding provided is woefully inadequate and is far less than that provided for diseases with similar outcomes and patient numbers. This needs to be changed. Extending research into understanding the causes of IPF and providing more effective treatments is a key aim of APF. A research fund has been established and potential for contribution to research projects is being identified.

Support is provided by the Charity for current and new research projects and travel awards have been made to enable young researchers to attend international conferences to extend their knowledge. The charity is also working to bring to the attention of major funders the need for increased research funds for IPF.

Fundraising and Donations

Action for Pulmonary Fibrosis depends entirely on donations and the funds raised by supporters to enable us to carry out our work.

The Charity trustees continue to be much encouraged by the number of individuals and groups across the UK who have undertaken a wide range of events and challenges to raise funds for APF. We also continue to be supported by many families through funeral donations in memory of loved ones who suffered from IPF.

The trustees of Action for Pulmonary Fibrosis are extremely grateful and appreciative of all donations which enable us to continue and extend our activities.

Plans for the Future

- APF trustees plan to continue the successful work of assisting in setting up more patient support groups which are needed across the country.
- The research fund will be promoted through a campaign to encourage activities that will contribute to building the fund.
- Work will continue and be extended in the provision of training for health professionals both in the specialist field and more widely in the community.
- The Charity will identify further specific project activities focusing on addressing issues faced by patients and their families.
- The Charity will continue to raise awareness of the disease across the pulmonary fibrosis community and to the general public.

Volunteers

In addition to the trustee role, trustees carried out the operational activities of the charity during the financial year as volunteers.

Grants

Action for Pulmonary Fibrosis makes grants to new patient support groups to help them to become established. This is on the basis that they will become self-sustaining within a year.

Public Benefit Statement

The charity trustees have complied with their duty to have due regard to the guidance on public benefit published by the Charity Commission in exercising their powers or duties.

Financial Results

The financial statements accompanying this report provide details of the income and expenditure for the year. Income for the year to 30 June 2015 was £202,121. This was raised almost entirely from individual donations and the many fundraisers who undertake a wide range of activities and challenges on our behalf and for which we are very grateful. One corporate grant of £19,600 was received during the year from Boehringer Ingelheim UK to assist in the setting up of new patient support groups. The level of income received during this year has enabled us to plan for more activities in the coming year and to establish a research fund with an initial sum of £100,000. Expenditure during the year was £34,105.

The Charity has no debt or guarantees. The Charity has no employees.

Financial statements are attached.

Reserves Policy

A reserves policy has been established which requires a minimum of 50% of projected annual core expenditure to be retained in a reserve fund. This was set at £30,000 for the year 2014-15 and is regularly reviewed.

This report was approved by the Board of Trustees on 9 January 2016 and signed on its behalf by

Michael Bray
Chairman of Trustees