Action for Pulmonary Fibrosis

Presentation to the St George's Fibrosis Support Group

16th October 2017

Action for
Pulmonary
Fibrosis

My story

Action for Pulmonary Fibrosis

Action for Pulmonary Fibrosis

- Established 2013 in Papworth
- UK charity dedicated solely to Pulmonary Fibrosis
- Run by Board of Trustees all with personal connections to PF
- Voice of the Patient Council

Action for
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The Trustee Team

Mike Bray – Founding Chair and Inspiration

Steve Jones (Chair)
Wendy Dickinson
Elizabeth Bray
Howard Almond

Professor Gisli Jenkins
Dr Helen Parfrey
Dr Simon Hart

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Fibrosis

Our Vision

A world in which **everyone** living with Pulmonary Fibrosis has a better future:

Supporting

Educating

Researching

Campaigning.

Supporting patients and carers . . .

45 PF Support Groups

- Peer support and education
- Initial funding and set up support
- Attend meetings and promote groups
- Share best practice – newsletter
- Learn from and support one another
- Fundraising

Voice of the Patient Council

- Listen
- Share
- Inform

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Educating…..

- **Public – raise awareness of the condition**
- **Healthcare professionals – provide education in primary care and share best practice (e.g., ILD INN sponsorship and lecture series)**
- **Members of Parliament and NHS - true figures of IPF patients in UK is unknown.**

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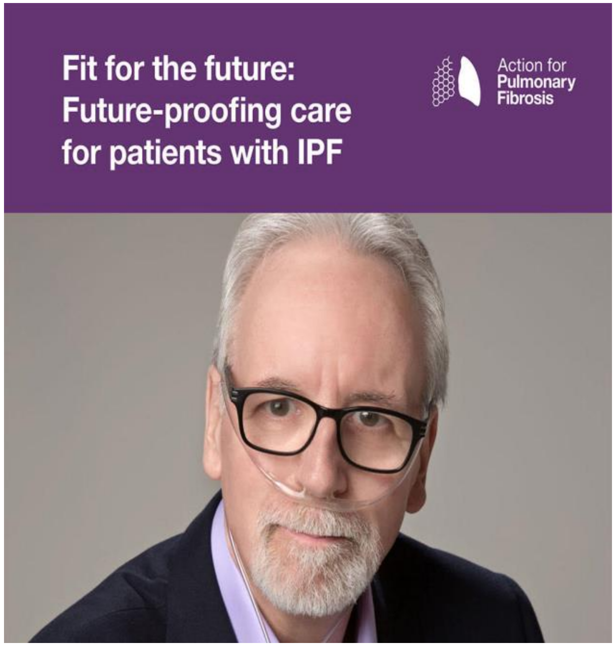
Campaigning for better care and support for PF patients and carers



Fit for the future: Future-proofing care for patients with IPF

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Campaigning for ……

- Implementation of NICE guidelines/Quality Standards
- Establishment of a registry of all patients diagnosed with IPF

Through…….

- NHS senior management
- UK Parliament All-Party Groups on Respiratory Health and Rare Diseases
- Scottish Parliament Cross-Party Group on Lung Health
- European IPF Federation (13+ countries) and European Parliament

Researching….

- Mike Bray Research Fellowship (£300,000 3–year research project into causes and treatments for IPF)
- Smaller grants for other research projects on ways to improve the quality of life of PF patients and carers
- Travel grants for researchers
- APF clinical trustees independently involved PF research (e.g., in Genomics England Study into DNA of IPF patients)

Fundraising

Raising Funds

Awareness

Run/Cycle/Swim/Trek

Fun

JustGiving.com

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What have we all achieved?

2010

NO

- Local support groups
- NICE IPF Recommendations
- Positive Clinical Trials
- Approved therapies
- Specialist networks

2017

YES

45 PF Support Groups

- NICE IPF Guidelines/Quality Standards
- Pirfenidone + Nintedanib
- PR and oxygen therapies
- Specialist centres + MDTs
- Action for Pulmonary Fibrosis
  - ✓ Support groups + networks
  - ✓ Voice of the Patient Council
  - ✓ Research Fund
- PFT + BLF Priority Area.

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Support Groups Strategy

APF committed to support patients and health care professionals to set up new support groups

Goals

- To ensure that all pulmonary fibrosis patients in the UK have access to a support group by 2022 – Currently 42 support groups need over 100 groups;
- To work with patients to develop new ways of serving people who live in remote areas or find it difficult to attend meetings;
- To support development of regional networks of support groups so that all have access to talks and information on the latest research and treatment options.

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Papworth PF Support Group

Established 2010

Patients from all over East Anglia

Meet every two months at Cambourne

<u>Plus</u>

- **Patient Awareness Day**
- **Annual Picnic**
- **River cruises on the River Ouse**

Patient run with close links to the Papworth ILD team

Working also to help new groups in East Anglia

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