



IRISH LUNG FIBROSIS ASSOCIATION LIMITED

Annual Report 2015

Irish Lung Fibrosis Foundation (ILFA) was incorporated as a Company Limited by Guarantee in 2003 and holds charitable status from the Revenue Commissioners. At the start of 2015 there were four directors, Professor Jim Egan, Nicola Goodbody (nee Figgis), Marie Sheridan and Terence Moran, the latter also acting as Company Secretary. During 2015 Marie Sheridan resigned as a Director and in 2016 three additional directors were appointed.

The Management Committee of ILFA met on eight occasions during the year to review ongoing matters, receive a report from the Honorary Treasurer and to attend to all matters relating to ILFA and its objects. Full Minutes of these meetings are prepared and circulated to all Committee members.

We now set out the main activities of ILFA during 2015.

One of the members of the Management Committee, Liam Galvin, was active throughout the year in the formulation and promotion of an “EU Patient Charter” – preliminary work on this had been undertaken by a former member of the Committee, Claire Tunissen. This was done through a series of meetings of equivalent organisations/bodies in various European countries having objects and aims similar to those of ILFA during which a Charter was produced seeking to raise awareness of Lung Fibrosis internationally and to reach a consensus between the participating bodies as to the rights and expectations of patients suffering from Lung Fibrosis and of their carers. Work on this project has continued in 2016 and has met with considerable success.

On a local level, Nicola Cassidy, another Committee member, was active in preparing a National Charter setting out what ILFA regards as legitimate rights/expectations of patients/carers under six headings as follows:

1. Early and accurate diagnosis;
2. Information and communication;
3. Medicines and Oxygen;
4. Pulmonary Rehabilitation and Exercise;
5. Lung Transplant Assessment;
6. Access to Additional Supports.

Following approval by ILFA of this National Charter, it was formally launched in October by one of the patrons, Senator Feargal Quinn, in the Oireachtas. This launch was attended by a number of TDs and Senators.

In addition to the Charter launch, a video was produced featuring a number of medical specialists and others discussing the various elements of the Charter.



As in previous years, ILFA hosted two Patient Information Days. These are opportunities for patients and carers to hear short speeches from various experts in the area of Lung Fibrosis, to ask questions and to meet with others in their position. In May, the meeting took place in Athlone where the speakers included Professor Jim Egan and Professor Anto O'Regan, both consultant respiratory physicians, Donna Langan respiratory nurse, Maria Love social worker and Matt Cullen who is a patient.

The second Patient Information Day was held in Dublin in November when the speakers included Dr Emmet McGrath, consultant respiratory physician.

Following on from the previous successful development of the "2000 Steps" exercise programme, ILFA commissioned and produced an Exercise DVD featuring a number of patients, physiotherapists from the physiotherapy department of the Mater Hospital and others. This has been distributed widely and is available for viewing on ILFA's website.

An Information leaflet on the use of Oxygen was produced in 2015.

ILFA produced and distributed three Newsletters to all our members including patients and carers, healthcare professionals and fundraisers who are registered on the database informing them of upcoming events, developments and access to information, services and local support groups.

A biennial prize in memory of Denise Cassidy was introduced in 2015. This is awarded on the basis of feedback from patients and others for those who give exceptional care to Lung Fibrosis patients.

Nicola Cassidy spoke at a number of scientific meetings including the AIR (Advancing in IPF Research) UK & Ireland meeting, London, in June, the European Respiratory Society Congress, Amsterdam, in September, the Irish Thoracic Society in November and the AIR meeting, Prague, also in November.

ILFA held its annual Service of Prayer and Reflection in Taney Parish Church in October.

A number of fundraising events were held during the year, principally by local volunteers in various parts of the country. These included donations from an Art Exhibition by Matt Cullen in Dublin which was opened by the then Minister of State for Children and Youth Affairs, Dr James Reilly, and the annual Pat Casey Memorial Cycle rally between Cork and Limerick.

Irish Lung Fibrosis Association
Registered Address: Lavery House, Earlsfort Terrace, Dublin 2
Postal Address: PO Box 10456, Blackrock, County Dublin
Enquiries: 086 871 5264
Website: www.ilfa.ie

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