



## **Dutch Pulmonary Fibrosis Society in 2010**

*Pulmonary fibrosis is progressive scarring of the lung tissue as a result of an interstitial lung disease. This eventually affects the ability to breathe and the supply of enough oxygen to the bloodstream is hindered. In general, scarring of the lungs is irreversible. Most cases of interstitial lung disease develop gradually, but some may occur suddenly. Medications can occasionally slow the process, but there is no cure. People with pulmonary fibrosis have to deal with many physical restrictions and this affects their social lives as well. The uncertainty of the course of the disease, the lack of adequate medicines and treatment, and the rarity and unfamiliarity of the disease burdens the patients and their families.*

The Pulmonary Fibrosis Society in the Netherlands promotes the interest of patients with pulmonary fibroses and their families. The society operates from the patient's perspective. Patients are the base of the society and they are closely involved in the policy of the society. Pulmonary fibrosis is a rare disease with only a couple of thousand cases in the Netherlands. The society is therefore small, but consists of active volunteers and an excellent and committed advisory board.

In short, our mission is to promote research for adequate treatment, to advocate for the pulmonary fibrosis issues, to promote disease awareness, and to provide a supporting environment for patients and their loved ones.

To achieve these goals, the society has developed many activities over the years. Currently, we are pleased to have established a clear information booklet, a functional website, and many other ways to inform patients and professionals. Knowledge of their disease will make patients stronger and help them get the best possible healthcare. Moreover, there is a well established program of support groups with national and regional meetings. In the national meetings, professionals are invited to present a specific subject within the interest of pulmonary fibroses. The regional meetings have a more informal character and the main goal is to exchange ideas and learn from each other's expertise. The society also has its own newsletter to keep members informed.

The Pulmonary Fibrosis Society has always been willing to collaborate with other organizations. As a result, the society is now participating in the research program of the Astma Fonds and will participate in the start of the new National Lung Association in the upcoming years.

With the help of a government grant, we have been able to employ a part time project manager over the last three years. Which has given a boost to our activities, improving communication and coordination. It has also enabled us to work towards a (high) standard for treatment in specialized centers for pulmonary fibrosis. This is a major and time costly project to achieve, but it will give patients more control over their situation and specialized centers will make it possible to provide optimal care for people with lung fibroses.

Achieving our goals in the last ten years is made possible by the many members and volunteers of the society. Which is even more admirable if you realize the seriousness of the disease and the mortality rate of pulmonary fibrosis. As a society, we hope we can continue to contribute to the quality of life of our members and keep an ambitious and forward looking agenda.

Drs. Ing. Riet Kulk,  
Secretary Pulmonary Fibrosis Society