

Dear \_\_\_\_\_,

As your constituent, I am writing to you regarding the Medical Card Review. I would like you to make representation to Expert Panel on Medical Need for Medical Card Eligibility to ensure they fully consider including Idiopathic Pulmonary Fibrosis (IPF) on the list of serious, chronic illnesses which will allow patients access to a full medical card. IPF is a rare, complex, progressive, debilitating and ultimately fatal lung disease of unknown cause. It is most typically seen in older people. It has a worse prognosis than many cancers. Patients' life expectancy is severely curtailed with an **average survival of 3 years** from the time of diagnosis

There are approximately 800 IPF patients in Ireland. With IPF, the lung tissue becomes irreversibly damaged and hardened with scar tissue (fibrosis) over a relatively short time period. The course of disease progression is highly unpredictable and some patients can deteriorate rapidly. Treatment options for IPF are limited; lung transplantation is the only viable option but this procedure is only available to a very small number of patients. Pirfenidone is the only licensed drug to slow down the progression of IPF in patients with mild to moderate IPF. There is no treatment available for patients with advanced or severe IPF.

As IPF is a progressive disease, patients will face increasing medical and palliative care needs in a relatively short time. Patients are at increased risk for respiratory infections and are likely to need frequent GP visits and hospitalisation to manage their condition. Costs associated with treatment, oxygen supplies and the associated electricity costs in particular, place a huge financial burden on patients and when it is possible to recoup costs, these can be months in being awarded. IPF patients are faced with huge financial hardship and should be entitled to a medical card based on their complex and progressive medical and care needs.

For more information on the condition, its impact and the submission made by the Irish Lung Fibrosis Association, please see [www.ilfa.ie](http://www.ilfa.ie).

Again, I urge you to make representation on this issue to the Minister for Health and Expert Panel on Medical Need for Medical Card Eligibility. I look forward to hearing from you in the coming days.

Yours sincerely

\_\_\_\_\_

Name

Address

Phone number

Email

Date