European Parliament
2014-2019

0026/2016

11.4.2016

WRITTEN DECLARATION

submitted under Rule 136 of the Rules of Procedure

on idiopathic pulmonary fibrosis

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Lapse date: 11.7.2016

0026/2016

Written declaration, under Rule 136 of Parliament's Rules of Procedure, on idiopathic pulmonary fibrosis[1]

1. Idiopathic diseases develop without a known cause. Idiopathic pulmonary fibrosis (IPF) is a chronic, progressive, fatal lung disease affecting older adults, not recognised as a rare disease in all EU countries.

2. In Europe, between 80 000 and 111 000 people live with IPF. Around 35 000 people are diagnosed annually.

3. After diagnosis, survival is between 2 and 5 years. There is no cure to reverse the disease but early diagnosis would allow an improved 'quoad vitam' prognosis.

4. Diagnosis and treatment are often delayed owing to insufficient information and an absence of diagnostic pathways.

5. Many patients lack timely access to pharmacological and non-pharmacological treatment because of funding delays and the exclusion of IPF from national health baskets.

6. Few IPF patients are eligible for lung transplants owing to inequality in the existing eligibility criteria in Europe.

7. The Commission is called upon to promote research on IPF to find its cause and cure.

8. The Commission is called upon to work in cooperation with Member States to enable access for IPF patients to orphan drugs and new medication approved by EMA.

9. The Commission is called upon to invite Member States to facilitate access to lung transplants and non-pharmacological treatment by promoting best practices and to recognise the role of healthcare professionals in IPF care.

10. This declaration, together with the names of the signatories, is forwarded to the Council and the Commission.

[1] Under Rule 136(4) and (5) of Parliament's Rules of Procedure, where a declaration is signed by a majority of Parliament's component Members, it is published in the minutes with the names of its signatories and forwarded to the addressees, without however binding Parliament.