

EU must do more to combat disease described as 'more lethal than most cancers'

Written by Andrey Kovatchev on 29 September 2014 in News
News

Idiopathic pulmonary fibrosis sufferers across Europe are struggling to receive consistent and equal access to care, argues Andrey Kovatchev.



It starts out as shortness of breath and dry cough. But it's more rapidly lethal than most cancers. Idiopathic pulmonary fibrosis (IPF).

It is one of the most frightening diseases you've never heard of. There is no known cause for this disease, which makes it increasingly difficult for the patient to breathe as it thickens the lungs. Only one or two out of five IPF patients survive five years.

An estimated 80,000 to 110,000 people in Europe live with IPF, and up to 35,000 new cases are identified each year. These numbers, however, do not reflect the full magnitude of the disease.

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IPF is often difficult to diagnose with initial symptoms resembling those of other, more common, diseases. What's worse is that IPF treatment options are limited and there are huge discrepancies in access to care between and within EU member states.

Access to the best available healthcare is a right for all European citizens. As an elected citizens' representative to the European parliament, it is my duty to voice the recommendations of the patient organisations that have come together to create the first European charter for patients suffering from IPF, calling for consistent and equal access to care and treatment.

This includes early and accurate diagnosis, better access to palliative care and end-of-life care as well as a holistic approach to standardise the management of the disease.

The EU has done a lot to ensure a high level of human health protection, yet there are still simple measures that should be implemented at both European and national level to improve the situation of thousands of patients living with this disease.

First, the EU can play a decisive role in the improvement of standards for IPF care across Europe by ring-fencing funding for research within the Horizon 2020 framework.

Second, the EU can create a Solidarity Fund to allow access to orphan drugs that, though having received European medicines agency (EMA) approval, are not yet sold in some member states due to delays in approval by national regulators.

Along with more than a dozen other members of the European parliament, I will formally endorse the first European IPF patient charter.

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We will also send a joint letter to the delegates of the expert meeting on chronic respiratory diseases to underline the importance of establishing multidisciplinary teams and regional networks to provide optimal care for IPF patients.

I firmly believe that the EU institutions must work together with member states to drive changes in national healthcare systems. National governments have a responsibility to influence clinical practice in partnership with local health authorities, medical societies and patient organisations.

If adopted, which we hope it will, the charter's recommendations will improve quality of life for all IPF patients across Europe, supporting the development of better long-term treatments and hopefully contributing towards finding a cure.

About the author

Dr Andrey Kovatchev is head of Bulgaria's EPP delegation in the European parliament

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[Health](#) [1]

[Research and Innovation](#) [2]

Categories

[Education and skills](#) [3]

[Health and social care](#) [4]

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[3] <https://www.theparliamentmagazine.eu/categories/education-and-skills>

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