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**It is high time for a holistic approach to COPD exacerbation including each suitable intervention to the risk profile** <http://ow.ly/iUok300hb8V>

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Received: May 03 2016 | Accepted: May 04 2016

Conflict of Interest: Disclosures can be found alongside the online version of this article at [erjersjournals.com](http://erjersjournals.com)

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*Eur Respir J* 2016; 48: 281–282 | DOI: 10.1183/13993003.00885-2016 | Copyright ©ERS 2016

# European idiopathic pulmonary fibrosis Patient Charter: a missed opportunity



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To the Editor:

The European charter for idiopathic pulmonary fibrosis is a welcome document [1], highlighting unmet needs in patients which will inform policy makers across Europe. However, it is sad that an important opportunity to involve children with interstitial lung diseases (ILDs) has been missed. There is a current pan-European paediatric ILD consortium [2] which could have been used to access these children and families. Our own work also highlighted similar themes [3]: diagnostic delay, the need for improved holistic care and written information, and also interestingly highlighted a previously undescribed issue, the high prevalence of feeding disorders in these children. So the European Charter, excellent as it is, sadly represents a lost opportunity to represent the needs of children with rare lung diseases to health commissioners.



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**Children with ILD should also have been included in the IPF European Charter**  
<http://ow.ly/ZBfA0>

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Received: March 10 2016 | Accepted: March 13 2016

Support statement: Funding information for this article has been deposited with FundRef.

Conflict of interest: None declared.

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*Eur Respir J* 2016; 48: 282–283 | DOI: 10.1183/13993003.00505-2016 | Copyright ©ERS 2016



### *From the authors:*

We would like to acknowledge the comments of A. Bush and colleagues on the European idiopathic pulmonary fibrosis (IPF) Patient Charter and seize the opportunity to provide additional information on this important initiative.

As described in table 2 of our article [1], the European IPF Patient Charter was an initiative driven by 11 established patient organisations active in the area of IPF, who approached the medical experts and healthcare professionals who authored the manuscript, to seek consensus on the key recommendations to be addressed to national and European policy-makers.

The patient organisations wanted to develop an advocacy tool on IPF with the intent of driving political action at both the European and national levels. IPF is one of the interstitial lung diseases (ILDs) that occur in adulthood [2], not in children, and is different to other types of lung fibrosis that could mimic IPF and could affect children (such as telomeropathies and familial pulmonary fibrosis). Hence, children and their families were not initially involved in this process.

Thanks to the work initiated with the European IPF Patient Charter, we are now laying the foundations for the setup of a European Reference Network on Rare Lung Diseases that will involve medical experts from different therapeutic areas to exchange best practices, and improve the diagnosis and treatment of patients with rare pulmonary diseases. We believe that the work conducted by the pan-European paediatric ILD consortium could bring an added value and we are therefore confident that a fruitful collaboration could be initiated within the framework of the European Reference Network.

It is our opinion that we could not have come to this important project without the European IPF Patient Charter. In a true spirit of collaboration, we hope that A. Bush and colleagues will agree that the European IPF Patient Charter paved the way for new and unexplored opportunities to improve care, and raise visibility of the needs of children and adults with rare lung diseases, which should be considered as an important success story rather than a missed opportunity.



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**The European IPF Charter paved the way to improve care and raise visibility of the needs of patients affected by ILD** <http://ow.ly/4nrVHV>

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