

As you know I am a patient with Idiopathic Pulmonary Fibrosis (IPF) and help run support groups for people affected by pulmonary fibrosis in Devon. I am a trustee of Action for Pulmonary Fibrosis the leading charity supporting many of the 70,000 people who currently have pulmonary fibrosis in this country.

This is a worrying time for people with pulmonary fibrosis. We have a very poor prognosis if we catch COVID-19 and researchers warn us that COVID-19 might result in a potential surge in cases which will have a massive impact on families, communities and the health service. COVID-19 induced fibrosis will increase the workload on the already busy respiratory services in both Torbay Hospital and the Royal Devon and Exeter hospitals which serve your constituency.

There are few treatments that are effective, and the current life expectancy for us as patients is just three to five years following diagnosis. There are, however, two medicines that can make a big difference to people living with pulmonary fibrosis: they are Pirfenidone and Nintedanib and they can slow down the progression of the disease in many patients.

At this time, under NICE guidelines, only people with the idiopathic form of the disease can access the drugs but in addition they also have to wait until their lung capacity declines to 80%. This is simply inhumane. The drugs do not repair lung function, they just slow down the inevitable progression, giving many more years of active and productive life.

So, people must wait for their lungs to deteriorate before being able to access treatment that might help to give them a longer, better, life. No one should have to go into hospital hoping that their disease has got *worse*, so they have a shot at getting better.

The UK is the only country in Europe and North America with this rule. We can and must do better.

I'm writing to you to ask for your support in getting universal access to Pirfenidone and Nintedanib. I would be grateful if you could write to the Secretary of State for Health and Social Care, and to Professor G Leng, Chief Executive of the National Institute of Health and Care Excellence (NICE) and ask them to end the restrictions that are preventing people like me from accessing a drug that could extend their life. Your support would mean a lot to me and to many friends both in Teignbridge and across the country battling this disease.