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Dr Falk Pharma UK welcomes European approval of disease name change from Primary Biliary Cirrhosis to Primary Biliary Cholangitis.

This week the European Association of the Study of Liver Diseases (EASL) approved a British initiative to change the name of the auto immune liver disease Primary Biliary Cirrhosis to Primary Biliary Cholangitis. Cirrhosis means inflammation or scarring of the liver, whilst Cholangitis means an inflammation of the bile duct - the true cause of this liver disease.

The name change came after the charity PBC Foundation UK surveyed its members earlier this year and found that only 5% were happy with the word cirrhosis being used to describe their condition. 80% of the 1,200 patients surveyed were in favour of a name change. These findings followed years of anecdotal evidence from patients who were suffering stigma and discrimination because of the inclusion of the word cirrhosis in their diagnosis.

PBC, which is mainly diagnosed in women between the ages of 40 and 55, is an auto immune condition for which there is no known cause. The body attacks the bile ducts leaving them unable to properly drain the liver of bile acid which leaks into the liver resulting in scarring and inflammation.

However, virtually all patients suffer from the assumption that their condition is caused by alcohol abuse or hepatitis and endure unfair judgement about their lifestyle. Currently a diagnosis of PBC means that patients are unable to obtain life insurance or mortgages, whilst other premiums such as travel or car insurance are significantly raised.

Dr Riadh Jazrawi, Medical Director of Dr Falk Pharma UK, which works closely with the PBC Foundation UK to educate and raise awareness around the condition, welcomes the decision.

'We are delighted that EASL have approved this change and believe that it will significantly improve the day to day experience of PBC patients,' says Dr Jazrawi. 'Historically cirrhosis was used in PBC because by the time most patients were diagnosed with the condition, the liver was indeed significantly damaged.'

'However today, thanks to earlier diagnosis and treatment such as ursodeoxycholic acid, only a minority of patients diagnosed will go on to develop significant liver scarring.

'Therefore the British initiative to change the name of Primary Biliary Cirrhosis to Primary Biliary Cholangitis is a significant and welcome step forward in improving the life of patients diagnosed with the condition. It will also enable the acronym for the condition, PBC, to be kept in use.

'We look forward to our colleagues in America and Asia supporting the name change in time for it to be included in the WHO International Classification of Diseases in 2017.'

Tony McFadyen, Managing Director of Dr Falk Pharma UK, comments:

'With the current focus on patient centred treatment, it is vital that disease names not only adequately describe the condition but also avoid stigmatising the patient.

'The data from the PBC Foundation survey indicates that the change from cirrhosis to cholangitis will be welcomed by PBC sufferers and we are delighted for them that this name change has been approved and congratulate the PBC Foundation on their huge achievement.'

To interview Dr Riadh Jazrawi or Mr Tony McFadyen contact Isla Whitcroft at Healthy PR on 01327 830222 or 07768 661189

