

British Liver Trust launches campaign to tackle late diagnosis of rare liver conditions

Thursday 26 February, 2026

The British Liver Trust has launched a new campaign ahead of Rare Disease Day to tackle the late diagnosis of rare liver conditions, after new analysis of patient survey data revealed that many people experienced symptoms before diagnosis, yet around a quarter of symptomatic patients had their concerns dismissed or were sent home without further investigation.

Liver disease is often associated with alcohol or lifestyle factors. But many rare liver conditions are autoimmune or genetic, affecting people of all ages, including babies, children and young adults. This misconception can contribute to delays in diagnosis and prevent people from seeking timely support.

Analysis of responses from more than 1,000 people living with rare liver conditions across the UK found that around one in five patients who experienced symptoms were diagnosed “very late”, when their disease had already progressed and treatment options were limited.

In response, the British Liver Trust has launched **No One Left Behind**, a new campaign aimed at shining a spotlight on rarer liver conditions that are too often under-recognised and misunderstood.

The campaign calls for greater awareness of early warning signs among healthcare professionals and the public, improved information and support at diagnosis, and greater investment in research.

Persistent itching, nausea, abdominal pain and jaundice were among the most commonly reported early warning signs across rarer liver conditions, including Primary Biliary Cholangitis (PBC), Autoimmune Hepatitis (AIH) and Primary Sclerosing Cholangitis (PSC). These are chronic, progressive diseases that often require lifelong specialist care. In some cases, delayed diagnosis can lead to cirrhosis, liver failure or the need for transplantation.

According to the British Liver Trust, tens of thousands of people in the UK are living with rare liver diseases, many of which can take years to diagnose due to a lack of awareness and limited research.

Emma was diagnosed with autoimmune hepatitis more than two decades ago, aged just 17, after developing severe itching and jaundice and spending weeks in hospital undergoing tests. At the time, she had never heard of the condition and did not recognise that her symptoms were signs of serious liver disease.

Emma said: “So many people don’t realise that liver disease doesn’t just affect people who drink alcohol. Conditions like mine are called ‘rare’, but they affect thousands of people.”

Rare Disease Day is marked globally each year on 28 February and aims to raise awareness of rare diseases and improve access to diagnosis, treatment and care for those affected.

Pamela Healy OBE, Chief Executive of the British Liver Trust, said:

“Rare liver diseases may be less common, but for the thousands of people affected across the UK, their impact is life-changing. Too often, a lack of awareness leads to delayed diagnosis and unequal access to specialist care. We need greater understanding, earlier diagnosis and sustained investment in research to ensure no one living with a rare liver condition is left behind.”

The British Liver Trust is the UK’s leading liver health charity and provides information, support and advocacy for everyone affected by liver disease. This includes people living with rare liver conditions such as autoimmune hepatitis, primary biliary cholangitis (PBC), primary sclerosing cholangitis (PSC), Alagille syndrome and biliary atresia.

For more information, visit www.britishlivertrust.org.uk.

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