

**First new medication for rare liver condition in nearly 20 years has potential to reduce liver transplant burden**

The PBC Foundation today welcomes the news that the first new treatment for 20 years has become available for patients with PBC. Affecting 22,000 patients in the UK, 90% of whom are women. Estimated that 1 in 1000 women over the age of forty have PBC, it is the single biggest cause of liver transplants among women in the UK.

The National Institute for Health and Care Excellence (NICE) approved the brand new treatment Obeticholic Acid (OCA) for patients living with PBC, for whom the first-line medication hasn't worked. Historically, this cohort of patients would have mainly progressed to transplant or death. By slowing down the rate of progression of liver damage, this medication has the potential to save many lives.

Professor David Jones, Director of the UK-PBC group which undertook much of the work that led to the approval of Ocaliva said "this is a really important day for PBC patients and a great example of patients, scientists, doctors, industry and regulators working together to make difference. We are also very grateful to the Medical Research Council and National Institute for Health Research for their support of PBC research. What is so important to say is that Ocaliva is manufactured in the UK and exported around the world so the UK is taking a lead in work that truly benefits people around the world. A good day"

"It is exciting news for PBC patients, and their families, that this new treatment option will now be available in England, Wales and Northern Ireland," said Collette Thain MBE, CEO of the PBC Foundation. "When I was first diagnosed with PBC, there was only one treatment option available and if that treatment failed, then there was no second option. Thankfully, since then, so much has changed for people living with PBC. After twenty years of advocacy on behalf of the PBC community, we now have a new treatment option, a growing awareness of the disease amongst the general public, world-leading expertise amongst UK clinicians and the acceleration of PBC research in the UK and around the globe."

It is an unprecedented move for NICE to have approved this new medication on its first attempt and we very much hope that this sets a new precedent for medications in the rare disease field. We are delighted that NICE are being supportive, innovative and progressive in their approach to bring thousands of patients hope, health and a longer life.

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## NOTES FOR EDITORS

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### **Contact for further information**

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### **What is PBC?**

PBC (Primary Biliary Cholangitis) is a long-term, auto-immune condition which affects the liver. In simple terms, the body thinks that the bile ducts within the liver are foreign objects and tries to destroy the lining to these ducts. These bile ducts are designed to allow the flow of bile from the liver, so damage of these ducts leads to poor drainage of bile acids. The bile acids then leak from the bile ducts, damaging surrounding liver cells, which then causes inflammation and scarring in the liver.

### **The PBC Foundation**

The PBC Foundation is the only UK organisation exclusively dedicated to providing support and information to those affected by Primary Biliary Cholangitis, an autoimmune liver condition with no known cause or cure. It supports over 9000 service users in 71 countries worldwide. For more information visit [www.pbcfoundation.org.uk](http://www.pbcfoundation.org.uk) or contact [collette@pbcfoundation.org.uk](mailto:collette@pbcfoundation.org.uk)

### **Intercept Pharmaceuticals**

Intercept is a biopharmaceutical company focused on the development and commercialization of novel therapeutics, including Ocaliva, to treat progressive non-viral liver diseases, including primary biliary cholangitis (PBC), nonalcoholic steatohepatitis (NASH), primary sclerosing cholangitis (PSC) and biliary atresia. Founded in 2002 in New York, Intercept now has operations in the United States, Europe and Canada. Intercept's International headquarters are located in London. For more information about Intercept, please visit [www.interceptpharma.com](http://www.interceptpharma.com).

### **National Institute for Health & Care Excellence**

The National Institute for Health and Care Excellence (NICE) provides national guidance and advice to improve health and social care. NICE's role is to improve outcomes for people using the NHS and other public health and social care services. We do this by:

- Producing evidence-based guidance and advice for health, public health and social care practitioners.
- Developing quality standards and performance metrics for those providing and commissioning health, public health and social care services.
- Providing a range of information services for commissioners, practitioners and managers across the spectrum of health and social care.

For further information visit: [www.nice.org.uk](http://www.nice.org.uk)

**UK-PBC**

UK-PBC is a unique collaboration between patient groups, doctors, scientists and industry with a shared interest in increasing understanding about, and treatment for the autoimmune liver disease Primary Biliary Cholangitis (PBC). For more info: [www.uk-pbc.com/](http://www.uk-pbc.com/)