

# PBC training course for HCPs



## ORGANISATION NAME:

Rarissimas – Associação Nacional de Deficiências Mentais e Raras

**COUNTRY:** Portugal

## CONTACT DETAILS

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## Project

Rarissimas continued their work to raise awareness of PBC in Portugal through the development of information and training activities. In collaboration with the Portuguese Society of Internal Medicine, and rare diseases and liver diseases working groups, Rarissimas developed a PBC training course for specialists and interns in internal medicine, gastroenterology and general practice/family medicine. The project also involved the translation of a Portuguese short film that was developed for PBC in 2016 into English, and the development of a pocket guide for PBC patients. The project was an extension of their first Practice to Policy project awarded in 2016.

## Objectives

The aim of the project was to raise awareness about PBC and how best to manage it, engaging caregivers, families and HCPs. In addition, it aimed to help patients manage their disease by registering their signs and symptoms on a pocket guide specifically designed to easily track symptoms.

## Key learnings

Despite collaboration with various organisations to raise awareness of the training programme, Rarissimas found that GPs expressed little interest in PBC training workshops, as they were too specific. Going forward, it would be beneficial to start raising awareness earlier and provide more context to GPs to encourage them to attend these training workshops.

The last major learning was that It is beneficial to collaborate with other liver disease organisations to conduct shared activities and reach a broader audience.

## Outcomes – What’s Next?

### Results

Since the beginning of the project, Rarissimas' helpline has observed a 192% increase in PBC information and support inquiries. Over the course of the year the project was implemented, ten news stories were secured. The video was shared with European PBC and liver disease patient organisations at International PBC Day 2018. The pocket guides were shared at events and will be provided to hospitals moving forward. In addition, twelve healthcare professionals attended the training course.

### Impact

PBC patients who used the helpline and pocket guide have found these tools to be helpful and aided their understanding of the disease as well as their own symptoms. Ultimately they are more empowered.

The feedback from training workshops was positive, with attendees commenting on the relevance of the events, which clearly addressed a need in the community.

### Next steps

The team want to continue supporting the PBC community to get to know and manage their disease better. Utilising their learnings from this project, they plan to promote training activities to GPs using a tailored approach. Additional plans include hosting training via webinars and translating the video into languages beyond English.