

## **A Declaration of Collaborative Working between ADVANZ PHARMA Services (UK) Limited and UK-PBC**

UK-PBC and ADVANZ PHARMA UK are engaged in a Collaborative Working project called “My Three Steps Patient Materials”.

### **Background:**

Fatigue is the most common clinical symptom experienced by PBC patients (with over 50% of patients experiencing it to some degree)<sup>1</sup>. Unfortunately, no licensed drug therapy improves it, making this a major area of unmet need in the disease. In addition, fatigue in PBC is inherently complex, with both peripheral and central components and several complicating and exacerbating elements<sup>2</sup>. The lack of a simple therapy, and this complexity, mean that clinicians appear to all too frequently avoid discussing it with patients<sup>3</sup>.

The PBC team in Newcastle have undertaken extensive work on the nature of fatigue in PBC and structured approaches to its management. They have now fully implemented the approach in a dedicated PBC fatigue clinic with a very high level of patient satisfaction. Their experience is that there is a clear need here, and the approach is successful. They have developed a suite of patient support documentation to explain their approach. Critical to the approach is a patient “ownership” of the symptom and the interventions to lifestyle that can improve it (own the problem; own the solution). This package will be expanded to include a live document, “My Three Steps”, which will bring together all the discussions in the clinic sessions and use them to identify the critical intervention steps that patients will take to help them to help themselves.

### **Project:**

The project will further develop the existing suite of patient support documentation for managing fatigue into a support pack called the ‘My three steps programme’. This support pack will be available to all UK clinicians and patient groups, either as a hard copy pack or as an electronic version for download from the UK-PBC website.

The project will start in February 2023 and run for six (6) months\*. The patient pack will remain “live” indefinitely however, for this collaboration, the patient pack will become the sole responsibility of UK-PBC after this agreement expires (2 years).

Both parties will contribute skills, experience and resources and significantly contribute to the initiative.

No clinical safety or outcomes will be measured as part of this project.

\*A contract amendment was signed in July 2023 to extend the length of this project by one year. The development of the patient support documentation is ongoing.

### **Benefits to patients:**

- Access to a support pack designed to inform patients about the steps they can take to improve their fatigue symptoms and their quality of life
- All UK clinicians will have access to the same support material reducing the variability in the support provided between clinicians and hospitals

### **Benefits to the NHS:**

- Healthcare Professionals provided with support materials to enable them to help their PBC patients manage their fatigue

**Benefits to ADVANZ PHARMA:**

- A greater understanding of the impact that fatigue has on PBC patients
- Understand how fatigue can be better managed

**References:**

1. Hirschfield GM, et al. Gut 2018;67(9):1568-1594.
2. Phaw, NA, et al. Dig Dis Sci 2021;66(7):2380-2386.
3. Abbas N. Critical shortfalls in the management of PBC: results of the first nationwide, population-based study of care delivery across the UK, EASL International Liver Congress 2022. London, UK. Presentation: OS137.