



# RESEARCH INTO COELIAC DISEASE – A PRIORITY SETTING PARTNERSHIP

Coeliac UK, working with the James Lind Alliance, has established a “Priority Setting Partnership” (PSP) to come to a consensus on the top ten most important questions about coeliac disease and other gluten related autoimmune conditions that are yet to be answered. The results of this work will inform our investment into research over the next few years.

A PSP is a tried and tested method of working, used by several other medical charities in recent years, which brings together a range of healthcare professionals and most importantly patients and their carers to examine the “unknown questions” about a medical condition. Each stakeholder brings their own unique perspective to the discussion to reach a common consensus about the top ten priorities for future research.

Supported by an adviser from the James Lind Alliance, the coeliac disease PSP is managed by a Steering Group which includes patients, parents of children with coeliac disease, GPs, dietitians, and experts in gastroenterology and neurology.

An initial survey of Coeliac UK members in June 2017 has produced a list of over 2,500 unanswered questions covering four broad themes:

- Cause
- Diagnosis
- Treatment
- Management

These have been analysed by an information specialist and collated into sub-themes. The Steering Group met recently and have formed “indicative questions” for each sub-theme which summarise the issues raised.

A second survey of Coeliac UK members (and others who have expressed an interest in the project) at the end of

this month aims to produce a shortlist of around 30 of these indicative questions.

In the New Year we will advertise for around 12 additional patients, carers and healthcare professionals to join the Steering Group for a day-long workshop in February. This group will be responsible for distilling the final shortlist and agreeing the top ten priorities for future research.

The results of the project will be announced at the Coeliac UK Research Conference at the Royal College of Physicians on 15 March 2018.

Coeliac Disease PSP Partners:



