

# Patient Association meeting, ICDS Paris, 7 September

## 1. Screening and diagnosis

- Who to screen, how to screen, when to screen
- Required gluten intake
- Recommendations on HLA-DQ testing

## 2. Post diagnosis care

- What care, when, how frequent and from whom?
- Ongoing symptoms
- Tools for self care
- Role of patient associations

## 3. Food safety

- International food standards; FAO / WHO / Codex Alimentarius
- International thresholds
- Food labelling – legislation and best practice
- Global certification programmes
- Consumer confidence
- Eating out – regulations and best practice
- Catering training and certification schemes
- Travelling

## 4. Celiac disease therapeutics

- Limitations of the gluten free diet, current state of research
- Patient associations' and patients' perspectives of the gluten free diet; their view on new treatments in development.
- Non responsive and refractory celiac disease
- Potential exclusion criteria eg due to genes, children versus adults.
- What is in the therapeutic pipeline, different approaches including immunotherapy; clinical and pre-clinical
- How can drug companies conducting international clinical trials work with patient associations?
- How does celiac disease fit into the larger picture of autoimmune diseases? What knowledge and understanding of celiac disease can be used to benefit other conditions and vice versa.
- What is the role of patient associations in clinical trial recruitment and/or data collection?