

# Annual Report & Financial Statement 2023

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CROSS PARTY GROUP ON COELIAC DISEASE  
AND DERMITIS HERPETIFORMIS

Chair: Rhun ap Iorwerth MS/AS  
Secretary: Tristan Humphreys

29<sup>th</sup> November 2023

## **1. Group membership and office holders**

### **Chair:**

Rhun ap Iorwerth MS/AS

### **Secretary:**

Tristan Humphreys – Head of Advocacy, Coeliac UK

### **Members:**

Rhun Ap Iorwerth MS/AS, Peredur Owen-Griffiths MS/AS, Mark Isherwood MS/AS, Russell George MS/AS, Mike Hedges MS/AS.

Tristan Humphreys (Secretary/Head of Advocacy, Coeliac UK), Fiona Newsome (Evidence & Policy Advisor, Coeliac UK), Claire Constantinou (Operational Lead Dietician, University Hospital of Wales), Dr Geraint Preest (Pencoed Medical Practice), Graham Phillips (Swansea Coeliac Group), Ian Severn (Cardiff Coeliac Group), Simon Scourfield (Operations Management Lead, NHS Wales Informatics Service), Sian Evans (Paediatric dietitian, University & Hospital of Wales), Dr Jill Swift (Consultant Gastroenterologist, retired), Alison Jones (Clinical Lead Prescribing Support Dietitian, Hywel Dda Health Board), Dr Vivek Goel (Spire Cardiff Hospital), Dr Ieuan Davies (Consultant Paediatric Gastroenterologist, University Hospital Wales), Dr Richard Cousins (Consultant immunologist, University hospital Wales), Gwawr James (National dietitian for special diets in schools, Wales Local Government Association), Eleanor Wilson (Senior nursing sister, Pencoed Medical Practice).

### **Previous Group Meetings since the last AGM.**

#### **Meeting 1.**

**Meeting date:** 31<sup>st</sup> January 2023

**Attendees:** Rhun ap Iorwerth MS/AS– Chair (RaI), Tristan Humphreys – Secretary/Coeliac UK (TH), Fiona Newsome (FN), Claire Constantinou (CC), Gwawr James (GJ), Ian Severn (IS), Dr Geraint Preest (GP), Russell George (RG), Dr Jill Swift (JS), Dr Richard Cousins (RC), Eleanor Wilson (EW), Mark Isherwood MS/AS (MI)

#### **Summary of issues discussed:**

- **Election of officers:** RaI was re-elected chair of the group (Nominated: MI, Seconded: MH). TH of Coeliac UK (CUK) was re-elected as secretary of group (Nominated: MI, Seconded: MH).
- **Cost, access and availability:** Coeliac UK's cost of gluten free (GF) food project is looking at the financial burden of GF food. The cost of living crisis is a real focus for the charity with ongoing work in this area through 2023. There will be an initial focus

on prescribing, mainly in England due to the withdrawal of provision by commissioners in recent years. Phase 2 will focus on retailer engagement and will link in with subsidy card scheme in Wales. The cost report is to be published in March 2023.

- **Parliamentary activity:** The All-Party Parliamentary Group (APPG) is launching an inquiry on diagnosis in the next few weeks and there would be a call for evidence to anyone who wants to participate. There will be evidence sessions in Westminster with a view to publishing a report before summer recess. Whilst the primary focus will be the health service in England, there will be much cross over and this will be relevant to the whole of the UK. CUK hopes to get a CPG running in Scotland. There was an event on diagnosis on 9 March with talks from CUK, health care professional champions and patient representatives.
- **Universal Primary Free School Meals:** The CPG wrote a letter to the Minister for Education and Welsh Language, Jeremy Miles MS/AS regarding access to Universal Primary Free School Meals (UPFSM) and received a positive response.
- **Gluten free food market:** the Gluten Free Food Market in Cardiff on 3 June was advertised where 30-40 manufacturers will be at Corner Stone Centre near Marks and Spencer.

## **Meeting 2.**

**Meeting date:** 8<sup>th</sup> June 2023

**Attendees:** Rhun ap Iorwerth MS/AS – Chair (RaI), Tristan Humphreys – Secretary/Coeliac UK (TH), Fiona Newsome (FN), Claire Constantinou (CC), Gwawr James (GJ), Ian Severn (IS), Dr Geraint Preest (GP), Dr Richard Cousins (RC), Eleanor Wilson (EW)

## **Summary of issues discussed:**

- **Cost campaign and surveys:** The [cost report was published](#) in March 2023 and an update on its impact on the community was given. Information on Phase 2 of the cost campaign was provided which focuses on retailers and a citizen science survey on availability and cost of gluten free in supermarkets. There was an update on the Wales Gluten Free Subsidy Card Scheme; NHS Shared Services have now taken over the running of the scheme from Hywel Dda University Health Board. CUK are part of the steering group. The health boards are in different positions, and this will be a slow process but there would be national support for delivery and administration. CUK has not met with Share Services yet but hopes to soon.
- **APPG diagnosis inquiry:** Update on APPG diagnosis inquiry and evidence sessions; the evidence sessions on diagnosis are now complete. The survey was still open if anyone wanted to contribute, and the link could be circulated around the group. The report will be written over the summer with the aim to launch the report at an event on 13th September in Westminster.

- **Scottish parliament event:** CUK hosted a diagnosis reception in March with the then Minister for Public Health, Maree Todd MSP. There was a good turnout and this has prompted further discussions on the rollout of the pathway in Scotland.
- **Awareness week:** There was an update on CUK's Awareness Week campaign '[coeliac disease is different for everyone](#)' which aimed to shine a light on under-recognised symptoms. It had been picked up by various media channels and there had been parliamentary activity too. In Wales, RaI submitted a Statement of Opinion as well as parliamentary questions (PQs). Mark Isherwood also submitted PQs and oral questions of the Minister. This had had an impact and Welsh Government has asked for a meeting with CUK.
- **Diagnosis pathway development:** There was an update on joint gastro pathway development proposal in England which is being developed by a cross-section of charities including Crohn's and Colitis UK. CUK has been invited to a meeting with Welsh Government to discuss the potential barriers that people with CD are facing and potential solutions to improving outcomes. Views on this were discussed.
- **REUL and gluten free food labelling law:** There have been some amendments to GF food labelling law as part of REUL. CUK had been working with the FSA and felt confident that they understood the issues. There are no implications for Wales at the moment.

## **2. Professional lobbyists, voluntary organisations and charities with whom the Group has met during the preceding year.**

### **Coeliac UK.**

3<sup>rd</sup> Floor,  
Apollo House,  
Desborough Road,  
High Wycombe.  
Buckinghamshire.  
HP11 2QW

**Annual Financial Statement.**

November 2023

Cross Party Group on Coeliac Disease and Dermatitis Herpetiformis.

**Chair:** Rhun ap Iorwerth MS/AS**Secretary:** Tristan Humphreys – Coeliac UK

<b>Group's Expenses.</b>	None.	£0.00
<b>Costs of all goods.</b>	No goods purchased.	£0.00
<b>Benefits received by the group or individual Members from outside bodies.</b>	No benefits received.	£0.00
<b>Any secretariat or other support.</b>	Secretariat provided by Coeliac UK. VC provided through Coeliac UK Zoom account.	n/a
<b>Services provided to the Group such as hospitality.</b>		
No catering or hospitality		
<b>Date</b>	<b>Description and name of provider</b>	<b>Cost</b>
	All meetings held via zoom	
	<b>Total cost</b>	<b>0.00</b>