

Annual Report & Financial Statement 2021/22

CROSS PARTY GROUP ON COELIAC DISEASE
AND DERMITIS HERPETIFORMIS

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

31st January 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), Ellie Wilson (Senior nursing sister, Pencoed Medical Practice).

Previous Group Meetings since the last AGM.

Meeting 1.

Meeting date: 30th June 2021

Attendees: Rhun ap Iorwerth MS/AS (RaI) – Chair/Cadeirydd Tristan Humphreys, Coeliac UK (TH) – Secretary/Ysgrifennydd, Peredur Owen-Griffiths MS (POG), Mark Isherwood MS (MI), Russell George MS (RG), Heledd Roberts (HR), Dr Ieuan Davies (ID),

Summary of issues discussed:

- **Welcome** – RaI welcomed attendees to the meeting and thanked them for giving their time. TH provided an overview of the work of the previous group.
- **Election of officers:** TH thanked RaI for offering to take over as Chair of the group and invited nominations from Members (as below). The following officers were then duly elected. Chair: Rhun ap Iorwerth MS (nom. MI, sec. POG) Secretary: Tristan Humphreys (nom. POG, sec. MI).

- **Future plans:** RaI invited TH to lay out the key priorities for the group in the months ahead. TH signposted new members to a Legacy Report the previous CPG put together drawing together its work to date and identifying some key priorities going forward. An executive summary of this can [be found here](#). TH drew particular attention to two areas of interest: Diagnosis and development of a clinical pathway.
- **Coeliac UK Research call:** TH highlighted the launch of Coeliac UK's research call and invited any members interested to get in touch to find out more. Coeliac UK is offering a pilot/proof of concept grant for research into coeliac disease in children and young people in partnership with the British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN).
- **Senedd committees and increased importance of CPGs:** RG noted the proposal for Senedd committees to meet less regularly and raised concerns over the impact this might have on their ability to scrutinise and effectively engage on a range of issues. With this in mind RG welcomed the good work of the CPG to date and felt there is an opportunity to have an even greater impact.
- **Meeting format – online meeting and bilingualism:** RaI proposed the group continue to meet online noting the increased flexibility this gives and the opportunity for added engagement with members in North Wales. This was unanimously agreed by the group. RaI also explained that the group would be seeking to work fully bilingually going forward.

Meeting 2.

Meeting date: 12th October 2021

Attendees: Rhun ap Iorwerth MS/AS (RaI) – Chair/Cadeirydd, Tristan Humphreys, Coeliac UK (TH) – Secretary/Ysgrifennydd, Heledd Roberts (HR), Dr Ieuan Davies (IHD), Dr Geraint Preest (GPr), Claire Constantinou (CC), Alison Jones (AJ), Dr Richard Cousins (RC), Rebecca Bowen (RB), Ian Severn (IS), Sian Evans (SE).

Summary of issues discussed:

- **Letter to Minister re: Endoscopy Services:** The chair has received a response from the Minister for Health and Social Services, Eluned Morgan MS, to his letter dated 22nd July re: Wales Endoscopy Service and the impact of Covid-19. It acknowledges the challenges facing people with coeliac disease in Wales and points to additional funding being provided by Welsh Government to deal with endoscopy backlogs as well as support being offered by the National Endoscopy Programme. IHD raised concerns that the National Endoscopy Programme does not cover children. The Chair acknowledged that this is something IHD had rightly mentioned previously and suggested the group go back to the Minister to raise this.
- **Blood tests:** TH provided an update on the blood test tube shortage across the UK. These are posing significant challenges with GPs being advised to rationalise testing. As a result of this and in the context of particularly acute winter pressures, Coeliac UK has decided to postpone its planned children's diagnosis campaign until next year

- **Coeliac Pathway-** TH provided a brief presentation to the group regarding the development of a potential coeliac pathway for Wales, drawing on feedback from members of the group and best practice from across the UK. There is clear evidence of need with significant obstacles to diagnosis as well as challenges regarding ongoing management. It was felt strongly by the group and acknowledged by the Welsh Government that a coeliac clinical pathway could deliver improvements to the patient journey.
- **Coeliac UK Devolved Nations strategy** - TH updated the group on the charity's adoption of a new Devolved Nation Strategy. The strategy seeks to ensure the charity works in a way that delivers equitably for its members across the UK, adopting a genuinely four nations approach to planning and delivery. TH thanked the group for its work over the years and for making the case for the positive impact engaging in the devolved nations can have.
- **Hywel Dda GF prescribing scheme** - AJ provided a verbal update on the scheme. To date 600 people are enrolled on it. That covers less than half of the GP practices and they are now rolling out in Ceredigion. This equates to around 60% uptake. One barrier that has been raised by those not taking up the card is an unwillingness to pay towards their prescriptions as the new scheme essentially subsidises the difference in cost rather than covering the cost in its entirety. AJ and colleagues are due to meet with the Chief Pharmacist for Wales, Andrew Evans, later this month to discuss next steps. A card holder survey has been carried out with 96% of those on the card preferring it to prescriptions. There is now a QR code patients can follow to find out more. Initial costings suggest that the scheme is cheaper than the existing prescriptions model whilst also providing support to more patients.
- **Laboratory closure-** RC drew the group's attention to the recent closure of the immunology lab at Prince Charles hospital covering Cwm Taf Health Board. It could have been foreseen and highlights a vulnerability in the system that many labs in the network are very small and can be easily impacted by staff changes.

Meeting 3

Meeting date: 4th May 2021

Attendees: Rhun ap Iorwerth – Chair (RaI), Tristan Humphreys – Secretary/Coeliac UK (TH), Sian Evans (SE), Heledd Roberts, Gwawr James (GJ), Dr Jill Swift (JS), Claire Constantinou (CC), Fiona Newsome (FN)

Summary of issues discussed:

- **Survey of dietitians:** CC has produced an anonymous survey and shared with dietitians in each health board (HB). So far, seven responses have been received. CC mentioned that there was a wide variation and little consistency in answers of what each HB is doing; only two out of the seven HBs have a clinical lead for CD. CC expressed the importance of a specialist dietitian seeing patients which is not necessarily possible in primary care services. CC welcomed the good practices and emphasised the importance of evaluation of services.
- **Verbal update from WLGA National Dietitian for Special Diets in Schools:**

RaI introduced GJ and welcomed the introduction of free primary school meals across Wales, recognising that it was an exciting time but one that posed many challenges. GJ explained her role as a dietitian working in WLGA, specifically looking at special diets. GJ explained the challenges of there being limited national guidance for managing special diets in schools and some schools were unable to provide gluten free (GF). GJ expressed concern that they have no data for the number of children on special diets in Wales; WLGA need this data to understand the impact for caterers and schools.

The expectation is that there will be an increase in demand for special diets when free school meals are rolled out. There is anecdotal evidence that children with CD often bring a packed lunch due to issues of trust. WLGA aim to develop a national agreed upon guidance for managing special diets to integrate with the existing legislation. They want schools to be involved in this process having long term collaboration between national and local organisations. They want to ensure provision is equitable across Wales and look at the financial implications of providing special diets.

RaI suggested that the CPG should write to the education minister to express its excitement at the rollout of universal school meals and the importance of involvement of dietitians in WLGA to ensure that special dietary needs are met, as well as asking what work is being done to find data on special diets before the introduction of this policy.

- **Gluten free prescribing-**

TH provided an update on current gluten free prescribing policy across the UK.

- **Northern Ireland** has a traditional prescribing model accessed through the GP. There is a restructure of the health service ongoing however this is not thought to effect commissioning in the short term.
- **Scotland** has a pharmacy led GF food service where prescriptions and annual reviews are managed by the pharmacy.
- **England** has a patchwork postcode lottery; half of the 106 CCGs have withdrawn prescriptions in some form. Following an England wide review in 2017, the Department for Health and Social Care blacklisted all products bar bread and flour mix. However crucially it left it to CCGs to set more restrictive local policies where they felt it reflected the needs of their populations. Essentially this set a ceiling of bread and flour mix but no floor. In July 2022, the 106 CCGs are due to be abolished in favour of 42 Integrated Care Systems (ICSs) and there is concern this could trigger a further wave of policy restrictions; TH expressed frustration that many consultations have been treated as tick box exercises with eventual decisions often in conflict with the evidence submitted and the majority opinion of respondents. Coeliac UK is writing to DHSC about this issue.
- AJ was unfortunately unable to attend due to illness, so TH offered to provide a partial update on the Hywel Dda scheme. The plan was to finalise and roll out the top up card scheme across Hywel Dda HB by end of April 2022. TH explained that

Welsh Government are keen on the project and would like to roll it out across Wales. TH emphasised that Welsh Government is planning a mixed model approach; the top-up card will run alongside traditional prescribing.

- **Update on Awareness Week & Children's Diagnosis Campaign-**

- Children's diagnosis campaign (April onwards)

There was a soft launch of Coeliac UK's children's campaign which includes videos, case studies and animations which can be found on CUK's website. This will be running across the year.

- Awareness Week activity (9th-15th May)

TH thanked RaI for the Statement of Opinion on Awareness Week in the Senedd to keep coeliac disease on the agenda and attract attention of Ministers. TH explained that diagnosis is an ongoing issue; Awareness Week is an opportunity to highlight that. TH gave an update on CUK's fundraising challenges that are linked to 1 in 100 (the number of people who have coeliac disease across the UK); there have been some impressive challenges and these case studies will be shared throughout the year.

Meeting 4

Meeting date: 20th September 2022

Attendees: Rhun ap Iorwerth – Chair (RaI), Tristan Humphreys – Secretary/Coeliac UK (TH), Gwawr James (GJ), Fiona Newsome (FN), Dr Ieuan Davies (ID), Dr Richard Cousins (RC)

- **Special diets in schools:** RaI has written to the Minister for Education and Welsh Language, Jeremy Miles MS/AS, regarding Universal Primary Free School Meals (UPFSM) and special diets. The group will be updated on any response at the following meeting.
- **Hospital Food:** TH provided an explanation of the Wrexham Maelor case where a lady with coeliac disease and other complex health conditions had sadly passed away after being fed gluten in hospital. At the inquest, a consultant geriatrician told the coroner that coeliac disease does not cause vomiting which is incorrect. Coeliac UK wrote to the coroner to clarify this and offer support. TH mentioned that many people had raised concerns with the coroner and as a result an independent expert has now been instructed to review the evidence. The inquest has been adjourned and will resume at a later date TBC. TH updated the group on CUK's broader activity around hospital food; calling for a review of hospital guidelines and increased training for healthcare professionals, as well producing a template letter for patients to share with their hospital prior to admission. CUK is also drafting a letter template to allow supporters to write to their local Health Boards or trust highlighting the importance of gluten free provision for patients with coeliac disease. Coeliac UK is in discussion with other charities and healthcare professionals regarding the challenge of special diet provision and food allergies in hospitals with a particular focus on the possible expansion of existing coloured wrist bands system as currently used for drug

allergies. There was a discussion in regard to the Chair writing a letter to the Minister for Health on the issue however it was felt by the group that it was best to hold off on writing to the Minister until the inquest has concluded.

- **Prescribing and cost:** TH provided an update on current gluten free prescribing policy across the UK. CUK is planning to write to the Department of Health and Social Care about the increasing limitations and varied provision of gluten free prescribing in England. AJ was unfortunately unable to attend due to illness, so TH gave an update on some key statistics regarding the Hywel Dda top up card scheme; uptake is at 63% and 92% of those who participated have said that they have a positive view on the card. FN gave an update on Coeliac UK's cost project and initial findings. There was a discussion about how Coeliac UK would use this information and how it would help the community. TH mentioned that it would be a useful tool for informing policy interventions and raising awareness of the challenges facing the community.
- **Westminster APPG:** TH updated the group on the formation of the APPG in Westminster which had been postponed due to the national period of mourning; the rescheduled meeting is likely to be next month (Update: 18th October 2022). TH mentioned that there had been a lot of interest.

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

Coeliac UK.

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Apollo House,
Desborough Road,
High Wycombe.
Buckinghamshire.
HP11 2QW

Annual Financial Statement.

January 2023

Cross Party Group on Coeliac Disease and Dermatitis Herpetiformis.

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

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