

Welsh Parliament Cross Party Group on Coeliac Disease & Dermatitis Herpetiformis

LEGACY REPORT – FIFTH SENEDD (EXECUTIVE SUMMARY)

8TH MARCH 2021

Officers: Dr Dai Lloyd MS (Chair)
Tristan Humphreys (Secretary)

Members: Rhun ap Iorwerth MS, Mike Hedges MS, Nick Ramsey MS

External Members : Alison Jones (*Clinical Lead Prescribing Support Dietitian, Hywel Dda Health Board*), Claire Constantinou (*Operational Lead Dietitian, University Hospital of Wales*), Dr Geraint Preest (*Partner, Pencoed Medical Centre*), Graham Phillips (*Group Organiser, Swansea Coeliac Group*), Dr Huw Jenkins (*Consultant Gastroenterologist*), Ian Severn (*Group Organiser, Cardiff Coeliac Group*), Dr Ieuan Davies (*Consultant Paediatric Gastroenterologist, University Hospital Wales*), Dr Jill Swift (*Consultant Gastroenterologist, University Hospital Wales*), Josh James (*Policy & Public Affairs Manager, Diabetes UK Cymru*), Rebecca Bowen (*Clinical Lead Dietitian Acute Nutrition PPH & Gastroenterology, Hywel Dda Health Board*), Dr Richard Cousins (*Consultant immunologist, University Hospital Wales*), Sian Evans (*Paediatric Dietitian, University Hospital of Wales*), Simon Scourfield (*Operations Management Lead, NHS Wales Informatics Service*), Tristan Humphreys (*Devolved Nations Lead, Coeliac UK - report author*), Dr Vivek Goel (*Consultant Gastroenterologist, Spire Cardiff Hospital*), Wayne Lewis (*Wales Policy Lead, Crohn's & Colitis UK*).

Welsh Parliament Cross Party Group on Coeliac Disease and Dermatitis Herpetiformis: Legacy Report

EXECUTIVE SUMMARY:

Purpose of report:

The upcoming election in May 2021 poses a number of challenges to the group. In particular there is a likelihood of change in membership with Members of the Senedd stepping down and new members being elected. The group therefore felt it was important to put on record the progress made to date whilst also highlighting potential areas for further work for the benefit of any future CPG. For the full report, please contact Tristan.humphreys@coeliac.org.uk

The Cross Party Group

The Cross Party Group (CPG) on Coeliac Disease and Dermatitis Herpetiformis is made of Members of Senedd, healthcare professionals and representatives from the coeliac community in Wales. It exists to discuss and promote the issues around coeliac disease and dermatitis herpetiformis. Initially set up in 2008 under the chairmanship of Dr Dai Lloyd MS, the current iteration of the group was established following the 2016 election. This report covers activity during the period 2016-2020.

Coeliac Disease

Coeliac disease is a serious, lifelong autoimmune disease that affects 1 in 100 people. For people with coeliac disease, the eating of gluten (a protein found in wheat, barley & rye) triggers an abnormal immune response in which the immune system attacks its own body. Symptoms include, but are not limited to, diarrhoea, vomiting, stomach cramps, mouth ulcers, fatigue, anaemia and neurological problems. The only current treatment is a strict gluten free diet for life. If undiagnosed or untreated there is a greater risk of complications including ongoing anaemia, osteoporosis, neurological conditions and in rare cases, small bowel cancer and intestinal lymphoma.

Work to date

The group has achieved significant progress in a number of areas and has increasingly played a vital role in shaping policy.

- Awareness raising: As part of Coeliac UK's Awareness Week campaign every May, engagement activity was held in the Senedd. In addition group members took part in regular media interviews and parliamentary activities.
- Decision support software: Development and promotion of decision support software to aid GPs. The software went live across Wales and was promoted to GPs accordingly however due to significant technical and behavioural obstacles, it was not pursued.
- Endoscopy services: The previous group undertook an investigation of the state of endoscopy services in Wales which included meeting with experts in the field and senior Welsh Govt. officials. Further, the Health, Social Care & Sport committee, also chaired by Dr Dai Lloyd MS undertook its own investigation into endoscopy services,

leading to publication of a report¹ in 2019. Progress has been severely impacted by the Covid-19 pandemic however no-biopsy strategies should help alleviate some of the pressure and whilst for the majority endoscopy will remain necessary, there is optimism that the service can begin to get back on track in the coming parliament.

- Serology (blood test) reporting: CPG member Dr Ieuan Davies and colleague Dr Richard Cousins undertook a project to improve serology reporting for children with coeliac disease in Wales. As a result a standardised response now accompanies any test results returned to the healthcare professional who requested it. This ensures the HCP is aware of appropriate next steps in the management of the child.²
- ACBS list: The Department of Health & Social Care decision to limit prescribing in England to bread and flour mixes only, poses a challenge to devolved policy makers as there is currently no alternative administrative framework for approving products in Wales. The decision was thus taken to freeze the Welsh list as of December 2018. Coeliac UK has been in discussion with representatives from the other devolved nations and the group plans to develop an alternative in the new parliament.
- Hywel Dda University Health Board top up card scheme; The CPG has been working closely with group member Alison Jones (Clinical Lead Prescribing Support Dietitian – Hywel Dda University Health Board) on an innovative pre-paid card prescribing scheme in Hywel Dda University Health Board³. The rollout of the scheme is still ongoing having been delayed due to the Covid-19 pandemic and to date c. 300 patients have been enrolled. The hope is for this to complete by the end of 2021.
- Meeting with Chief Pharmacist for Wales: Coeliac UK met with Andrew Evans in January 2019 and it was confirmed that his preference was for a mixed model of prescribing support in Wales, both of traditional prescribing and the Hywel Dda Model.
- Public Sector Settings: Supporting children with medical needs in schools: The group heard of significant issues facing children with healthcare needs in school. Support was said to vary from school to school and lacked clarity for both parents and teachers. Engagement around this issue has been led by the Care in Schools Alliance (CISA) Wales, a grouping of 20 healthcare professionals and charities chaired by Coeliac UK. This led to significant improvements to *Supporting Learners with Healthcare needs' guidance*⁴ as well as an amendment to the *Additional Learning Needs and Education Tribunal (Wales) Act 2018* to ensure greater statutory protection for children with medical needs in school. Finally, Coeliac UK as a member of the WLGA's special diets working group helped developed all Wales best practice guidance for special diets set to be rolled out in 2021.
- Public Sector Settings: Hospital food: The group held a discussion on the challenges facing coeliac patients in hospitals. This builds on previous engagement with health

¹ Endoscopy Services in Wales, Health, Social Care & Sport Committee, April, 2019.

<https://senedd.wales/laid%20documents/cr-ld12492/cr-ld12492-e.pdf>

² Senedd Cross Party Group on Coeliac Disease minutes, December 2020

<https://business.senedd.wales/mgIssueHistoryHome.aspx?lId=15002>

³ Senedd Cross Party Group on Coeliac Disease, March 2019

<https://business.senedd.wales/documents/s87712/Minutes%20of%2019%20March%202019.pdf>

⁴ Supporting Learners with Healthcare Needs, Welsh Government guidance, March 2017

<https://gov.wales/sites/default/files/publications/2018-12/supporting-learners-with-healthcare-needs.pdf>

boards regarding 'All Wales Nutrition and Catering Standards for Food and Fluid Provision for Hospital Inpatients'. Further, Coeliac has been in talks with Philip Shelley, Chair of the UK Government's independent review into hospital food in England⁵. The charity also expects results from a survey of its members' hospital food experiences in summer of 2021.

- **Wales Gluten Free Food Show:** In October 2017, the first of three annual Wales Gluten Free Food Shows were held by Coeliac UK, the largest gluten free specific show in the UK. Held in Cardiff, the event showcased more than 20 gluten free food businesses as well playing host to dietetic clinics, expert speakers and panel debate discussions, Chaired by Dr Dai Lloyd MS. The three shows attracted a total of more than 4,500 attendees. The show was put on hold subject to the Covid-19 pandemic and unfortunately is unlikely to be held by Coeliac UK in the near future due to cost implications.

Key challenges for the new parliament:

Diagnosis: *Wales has the lowest diagnosis rates for coeliac disease in the UK*

- *Only 29% (c.22k) of those estimated to have the condition in Wales are currently diagnosed. On average it takes 13 years from onset of symptoms to achieve a diagnosis⁶. One in 4 people with coeliac disease have previously been misdiagnosed with irritable bowel syndrome (IBS)⁷.*
- *Despite progress in recent years, awareness of coeliac disease remains low amongst both public and healthcare professionals.*
- *Endoscopy waiting times are lengthy (c.65% waiting longer than 8 weeks) and needed progress has been undone by the Covid pandemic. This is likely even worse for people with coeliac disease.*

Management: *Access to appropriate support and high quality gluten free food remains inconsistent and too often public sector settings are found wanting.*

- *Access to gluten free staples on prescription is a crucial means of supporting adherence to the gluten free diet. Gluten free staples continue to be available on prescription in Wales and new initiatives such as the Hywel dda top up card scheme are testing alternative approaches. However changes to the ACBS list in England risk limiting choice of certain products in Wales.*
- *Support for people with coeliac disease in public sector settings continues to be of concern. Provision is often variable and there can be a lack of knowledge from frontline staff. Whilst significant progress has been made in schools in recent years thanks to new legislation and guidance, there is an opportunity for further work improving gluten free provision in hospitals.*

⁵ Report of the Independent Review of NHS Hospital Food, Shelley P. October 2020

<https://www.gov.uk/government/publications/independent-review-of-nhs-hospital-food>

⁶ Violato, M. and Gray, A. (2019) "The impact of diagnosis on health-related quality of life in people with coeliac disease: a UK population-based longitudinal perspective," BMC Gastroenterology. Springer Science and Business Media LLC, 19(1). doi: 10.1186/s12876-019-0980-6.

⁷ Card, T. R. et al. (2013) "An excess of prior irritable bowel syndrome diagnoses or treatments in Celiac disease: evidence of diagnostic delay," Scandinavian Journal of Gastroenterology. Informa UK Limited, 48(7), pp. 801–807. doi: 10.3109/00365521.2013.786130.

Thanks

The group would like to put on record its gratitude to all those that have taken time to make the CPG a success. Members contributed to lively and well informed discussion during meetings and have worked hard to put ideas into practice outside of them. Particular thanks are due to Dr Dai Lloyd MS (Chair) and Rhun ap Iorwerth MS for being ever present at meetings, for steering the group during a productive period and for their determination to ensure the group delivered for people with coeliac disease across Wales. We would also like to record our thanks to their support staff and in particular Marcia Spooner for her help in administering the group.

We would also like to once again put on record our gratitude to all those CPG members who have worked tirelessly during the Covid-19 Pandemic. We know they have faced daunting pressures and unprecedented challenges. That they have met this moment whilst still continuing to contribute to the improvement of the lives of the coeliac community is to be commended.

To all the Members of the Senedd standing in May, we wish you the very best for the election and look forward to welcoming you back to a new CPG in the next parliament.