

Grŵp Trawsbleidiol ar Glefydau Seliag a Dermatitis Herpetiformis Cross Party Group on Coeliac Disease & Dermatitis Herpetiformis

Date & time: Thursday, 8 June 2023, 12-1pm
Venue: Zoom

Attendees: Rhun ap Iorwerth – 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)

No.	Item
1	<p>Apologies for absence:</p> <p>Dr Ieuan Davies, Llyr Gruffydd, Peredur Owen Griffiths, Graham Phillips</p>
2	<p>Minutes of last meeting</p> <p>The minutes of the last meeting were approved.</p>
3	<p>a. Update on campaign and report</p> <p>FN gave an update on the cost report which was published in March 2023 and its impact on the community. As well as provided information on Phase 2 of cost campaign which focuses on retailers and on citizen science survey on availability and cost of gluten free in supermarkets.</p> <p>b. Citizen science food shopping survey c. Update on meeting with Trussel Trust</p> <p>TH updated the group on CUK meeting with Trussel Trust (TT). TH mentioned that TT felt confident those who need gluten free could access it, but people should be accessing support through other means before going to food bank. TH mentioned that this is an ongoing conversation and will keep the group updated.</p> <p>d. Prescribing update</p> <p>TH gave an update on prescribing in England since 106 Clinical Commissioning Groups had merged to become 42 Integrated Care Boards. TH shared an update on the Wales Gluten Free Subsidy 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. TH told the group that 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. TH emphasised the importance of a transparent accurate process.</p>

5	<p>Parliamentary activity</p> <p>a. Update on APPG Diagnosis Inquiry and evidence sessions</p> <p>TH updated the group on the APPG diagnosis inquiry and evidence sessions; the evidence sessions on diagnosis are now complete.</p> <p>TH asked if anyone would also like to provide evidence to the inquiry, the survey is still open, and the link could be circulated around the group (https://www.surveymonkey.co.uk/r/F3J5WRV). TH said that the report would be written over the summer with the aim to launch the report at an event on 13th September in Westminster.</p> <p>b. Update on Scottish Parliament event</p> <p>TH told the group that CUK hosted a diagnosis reception in March with the then Minister for Public Health, Maree Todd MSP and that there had been good turnout. This has prompted further discussions on the rollout of the pathway in Scotland.</p>
6	<p>Awareness week</p> <p>a. Update on CUK activity</p> <p>TH updated the group on CUK's AW campaign 'coeliac disease looks 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.</p> <p>b. Statement of opinion</p> <p>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. TH mentioned that this had had an impact and Welsh Government has asked for a meeting with CUK.</p>
7	<p>Diagnosis Pathway Development</p> <p>a. England Gastro pathway</p> <p>TH gave 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. TH agreed to keep the group updated.</p> <p>b. Invitation to meet with Welsh Government</p> <p>TH mentioned that 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. TH asked if anyone from the group had any views on this.</p> <p>GP emphasised the importance of awareness raising and HCPs recognising the non-gut related symptoms. He mentioned that it was important that practice nurses, healthcare assistants and pharmacists have a better understanding of the condition. GP also mentioned that the pathway can cause issues, the process needs to be quick, and a gluten containing diet is continued until they have seen the specialist. GP mentioned he was happy to be included in discussions if CUK needed.</p>

	<p>EW asked about paediatric clinical pathway and from her experience, the plan was less obvious. RaI requested that the paediatric pathway is mentioned to Welsh Government. TH mentioned that the no-biopsy pathway was more established than in adults, but that the paediatric pathway should not be forgotten about in the discussion.</p> <p>CC mentioned that there is no dedicated workforce for CD, and it is not very well funded in dietetics. She thought that dietetic led service for CD would be beneficial. CC emphasised the importance of the longer-term pathway and follow-up alongside diagnosis.</p> <p>GP echoed this and mentioned it was important to have clarity about whether a patient is being followed up in primary or secondary care and if it is primary care, there needs to be funding and better education as there is currently not the capacity.</p> <p>CC suggested primary care dietitians and Patient Initiated Follow-Up (PIFU) set-ups, so services are responsive to a patient's circumstances and available when needed.</p> <p>IS mentioned awareness was key and local groups could be used for expertise, working with dietitians.</p>
8	<p>AOB</p> <p>TH mentioned that there had been some amendments to GF food labelling law as part of REUL. TH assured the group that CUK had been working with FSA and felt confident that they understood the issues. There are no implications for Wales at the moment, but RaI asked to be kept updated on this.</p>
9	<p>Dates for future meetings</p> <p>RaI said a date would be circulated closer to the time</p>

Actions	Member
Circulate link to inquiry	FN/TH
Circulate minutes and potential dates for next meeting	FN/TH