

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

Date & time: Tuesday, 31st January, 12:00-13:00
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), Russell George (RG), Dr Jill Swift (JS), Dr Richard Cousins (RC), Eleanor Wilson (EW), Mark Isherwood (MI)

No.	Item
1	<p>Apologies for absence:</p> <p>Dr Ieuan Davies, Alison Jones, Rebecca Bowen, Llyr Gruffydd MS/AS</p>
2	<p>Minutes of last meeting</p> <p>a. Amendments and approval of the Minutes The Minutes were approved as accurate by the group.</p> <p>b. Matters arising</p> <ul style="list-style-type: none"> Letter to Minister re: UPFSM <p>TH gave an update on the letter from the CPG to the Minister for Education and Welsh Language, Jeremy Miles MS regarding access to Universal Primary Free School Meals (UPFSM) and received a positive response. RaI thanked TH for the letter and emphasised the importance of having these pledges in black and white.</p> <ul style="list-style-type: none"> Delay to Welsh Government Gluten Free Food Subsidy meeting <p>TH told the group that the meeting had been delayed until early February and those updates will be given at the next CPG meeting.</p> <ul style="list-style-type: none"> Discussion about meetings <p>RaI asked if the group was happy with the virtual meetings. RG said he had been to a number of hybrid CPGs and they worked well but advised that having an IT technician on hand was important in case of IT issues. It was agreed that attendance was better for virtual events but it was also nice to see people in person. RaI suggested that the meetings continue online but if there is an occasion where it would be useful to meet in person, it is something that can be arranged.</p> <ul style="list-style-type: none"> Gluten free food market <p>IS informed the group of the Gluten Free Food Market in Cardiff on 3 June where 30-40 manufacturers will be at Corner Stone Centre near Marks and Spencer. It was agreed that the information would be sent to Coeliac UK to be distributed to the group once confirmed.</p>

3	<p>AGM</p> <p>a. Election of officers</p> <p>RaI was reelected chair of the group (Nominated: MI, Seconded: MH). TH of Coeliac UK (CUK) was reelected as secretary of group (Nominated: MI, Seconded: MH).</p> <p>b. Approval of financial statement</p> <p>The financial statement was approved. TH explained that the report was just a summary of the previous meetings and there has been no direct expenditure.</p>
4	<p>Cost, access and availability</p> <p>a. Presentation of preliminary findings from CUK cost project (FN)</p> <p>TH gave a brief background on Coeliac UK's cost of gluten free (GF) food project which is looking at the financial burden of GF food and mentioned that 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 the next few weeks.</p> <p>FN gave a presentation on CUK's findings and offered to circulate the report on publication.</p> <p>b. Questions and answers</p> <p>CC emphasised the issue of access and availability and asked what CUK are doing to combat this. FN mentioned that the work on cost is part of a wider project looking at cost, access and availability which will be examined in more detail in phase 2 of the campaign. TH told the group that CUK aims to produce a survey on access and availability at supermarkets and will be asking supporters to attend supermarkets to complete the survey; this will fit in with phase 2 retailer engagement.</p> <p>RaI asked how the CPG could help support with the cost report and whether the group should be preparing to join the campaign. CC said that it would be good to get the health boards (HBs) involved to promote the survey. RaI said that the group could draft a letter from RaI to go to the HBs to ask them to promote the survey and share information.</p> <p>TH agreed and said that CUK would share the report with the group. He emphasised the challenge of framing the engagement in Wales due to different policy answers across UK but that the data would be useful for informing the subsidy level in the Gluten Free Food Subsidy in Wales.</p>

	<p>GP highlighted the importance of reinforcing the roles of doctors and clinicians and the importance of dietary compliance, particularly for patients with mild symptoms. Cost plays a significant role in adherence, and this can lead to long term consequences for the patient and the NHS. GP wondered if a non-profit provider could source GF products in bulk and then provide it cheaply.</p> <p>CC agreed with GP and asked whether CUK has linked in with the Trussel Trust (TT) to identify the number of those trying to access GF food from food banks and the amount of food suitable. RaI reinforced this and asked whether any work has been done on the gluten free diet and poverty.</p> <p>TH reassured the group this was on CUK's agenda and that he had a meeting with TT scheduled in the coming week. He also pointed to work the charity had done around development of resources on the gluten free diet for food banks. The group agreed that fundamentally the most vulnerable need to be able to access GF food. RaI asked if TH could give an update of the meeting with TT at the next meeting to see what the group might be able to do to help.</p> <p>CC asked whether leaflets for GF products could be distributed by TT and how apps like 'Olio' and 'Too Good To Go' could be used to support coeliac community.</p>
5	<p>Parliamentary activity</p> <p>a. Update on re-establishment of APPG in Westminster</p> <p>TH mentioned the group is launching an inquiry on diagnosis in the next few weeks and that there would be a call for evidence to anyone who wanted to participate. There will be evidence sessions in Westminster with the 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.</p> <p>b. Scottish Parliament event</p> <p>TH told the group that CUK hoped to get a CPG running in Scotland and that there was an event on diagnosis on 9 March with talks from CUK, health care professional champions and patient representatives.</p> <p>RaI welcomed any ideas for inquiries on any particular areas and asked about ways the CPG could interact with its counterparts in Scotland and England.</p>
6	<p>AOB</p> <p>TH let the group know that Awareness Week would be taking place 15-21 May with the focus on diagnosis.</p> <p>JS mentioned that she has now retired and this would be her last meeting. RaI and TH thanked for the significant support she has provided over the years.</p>
7	<p>Dates for future meetings</p> <p>RaI said a date would be circulated closer to the time</p>

Actions	Member
Circulate information on the Gluten Free Food Market to CUK for distribution to everyone	IS
Circulate cost of gluten free diet report	TH
Circulate minutes and potential dates for next meeting	TH