

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

Date & time: Dydd Mercher 30 Mehefin 2021, 11.00-11.45  
Wednesday 30 June 2021, 11.00-11.45  
Venue: via Zoom

*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),*

	Item
<b>1</b>	<p><b>Apologies for absence</b></p> <p>Graham Phillips, Alison Jones, Dr Jill Swift, Dr Geraint Preest, Dr Richard Cousins.</p>
<b>2</b>	<p><b>Welcome</b></p> <p>RaI welcomed the group and thanked new members and old for giving their time to support the re-establishment of the CPG. He highlighted the importance of having a voice for the coeliac community in the Senedd.</p> <p><i>Overview of the group</i></p> <p>TH explained the priority for the inaugural meeting was primarily to re-constitute the group and elect a new Chair and Secretariat. The desire to do so quickly is to build on the work of the previous group and reflects its effectiveness in the previous Senedd. TH commented on the good mix of health care professionals, members and patients represented on the group and highlighted what an asset it had been to the coeliac community in Wales.</p>
<b>3</b>	<p><b>Election of Officers</b></p> <p>TH thanked RaI for offering to take over as Chair of the group and invited nominations from Members (as below).</p> <p>The following officers were then duly elected.</p> <p><i>Chair: Rhun ap Iorwerth MS (nom. MI, sec. POG)</i> <i>Secretary: Tristan Humphreys (nom. POG, sec. MI)</i></p>
<b>4</b>	<p><b>Future plans</b></p> <p>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 identified some key priorities going forward. An executive summary of this can be found <a href="#">here</a>. TH drew particular attention to two areas of interest; Diagnosis and development of a clinical pathway.</p>

	<p>Firstly, <b>underdiagnosis and misdiagnosis</b> of coeliac disease continues to be a significant challenge in Wales and across the whole of the UK. Only around 30% of people with coeliac disease have a diagnosis which amounts to roughly half a million who don't and as such are running the risk of long term associated conditions.</p> <p>ID raised the challenges around endoscopy waiting times and in particular the impact Covid has had on them. Significant progress had been made on the issue in the years up to 2020 but unfortunately the pandemic has derailed that. There was virtually no elective work going last year and there is a lengthy backlog of elective work and investigative treatment that's required. From an adult perspective it will likely take years to catch up. In turn the concern is that this will concentrate on cancer, inflammatory bowel disease etc at the expense of coeliac disease. This could have worrying impacts on diagnosis.</p> <p>RaI proposed a letter to the Minister requesting a situation report of where the health service is with regards endoscopy and indeed diagnosis more generally.</p> <p><b>ACTION: TH to draft letter to the Minister and share with RaI.</b></p> <p>Secondly, the group has shown a particular interest in development of a <b>clinical pathway for coeliac disease</b>. There has been some interesting work done on this in Scotland and they've made some good progress on it through their <a href="#">Modernising Patient Pathways Programme</a>. However we're at a fairly early stage here in Wales. TH invited ID to share his thoughts on this particular area.</p> <p>ID agreed that this was something the group should be focussing on. He laid out his vision of a disease specific clinical pathway that encompasses both children and adults. The principles should be equity of access, ensuring that that patients whether they be children, young people or adults are investigated appropriately, diagnosed in a timely fashion, have the disease explained to them by an expert, and then have the gold standard of follow up and care. ID also referenced the need to dovetail with existing guidance and argued there was an opportunity for Wales to lead the way on this work.</p> <p>ID described development with regards pediatrics that might tie in with this piece of work. There is slight realignment of tertiary level, gastroenterology taking place with centralisation of diagnosis for South and Mid Wales through Morryston hospital in Swansea. This should ensure that people get rapid expert advice, and information early on, and then whatever can be delivered close to home is delivered close to home. This is the model being recommended for children, and would, ID argued, make sense through the entire patient's life.</p> <p>RaI suggested the group was well placed to bring together the relevant stakeholders and expertise to sketch out such a pathway and could begin to look at this project at the next meeting.</p> <p><b>ACTION: TH to solicit views of key stakeholders re: clinical pathway and present to group at next meeting.</b></p>
<p><b>5</b></p>	<p><b>Coeliac UK Research call</b></p> <p>TH highlighted the launch of Coeliac UK's research call and invited any members interested to get in touch to find out more.</p>

	<p>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).</p> <p>Researchers are invited to submit applications to this call that will underpin Coeliac UK's top ten research priorities and can apply for up to £15k for a maximum of 18 month project. For more information, they can contact Research Officer, Alice Andrews, using the <a href="#">online enquiry form</a>.</p> <p>RaI requested a research update at a future meeting.</p> <p><b>ACTION: TH to schedule research update from Coeliac UK at future meeting.</b></p>
<b>6</b>	<p><b>Senedd committees and increased importance of CPGs</b></p> <p>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 RD welcomed the good work of the CPG to date and felt there is an opportunity to have an even greater impact. Rai agreed that this was a real concern and places an added onus on CPGs in the health field.</p>
<b>7</b>	<p><b>Meeting format – online meeting and bilingualism</b></p> <p>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.</p> <p>RaI also explained that the group would be seeking to work fully bilingually going forward. There are some technical issues with accessing Zoom Pro licenses but hopefully this will be resolved soon. Working bilingually also should be easier online. Everything else, in terms of letters and communications will be bilingual as well.</p>
<b>8</b>	<p><b>Date of next meeting.</b></p> <p>The next meeting will take place in the Autumn. Date to follow.</p> <p><b>ACTION: TH to liaise with members and share dates for future meetings.</b></p>

<b>Actions</b>	<b>Member</b>
<b>ACTION: Draft letter to the Minister and share with RaI.</b>	TH
<b>ACTION: Solicit views of key stakeholders re: clinical pathway and present to group at next meeting.</b>	TH
<b>ACTION: Schedule research update from Coeliac UK at future meeting.</b>	TH
<b>ACTION: Liaise with members and share dates for future meetings.</b>	TH

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

Dyddiad ac amser: Dydd Mercher 30 Mehefin 2021, 11.00-11.45

Lleoliad: trwy Zoom

*Rhun ap Iorwerth AS/MS (RaI) – Cadeirydd/Chair (i'w gadarnhau)*

*Tristan Humphreys, Coeliac UK (TH) –Ysgrifennydd/Secretary (i'w gadarnhau)*

Rhif	Eitem	Noddwr	Amser (munudau)
1	Ymddiheuriadau	TH	
2	Croeso <ul style="list-style-type: none"> <li>• Croeso gan TH a throsolwg o'r grwp</li> <li>• Cyflwyniadau byr.</li> </ul>	TH	10
3	Ethol Swyddogion / CCB <ul style="list-style-type: none"> <li>a. Enwebiadau / eilio</li> <li>b. Pleidleisio</li> </ul>	TH	5
4	Amser / fformat cyfarfodydd <ul style="list-style-type: none"> <li>a. Trafodaeth</li> </ul>	TH	5
5	UFA / Cwestiynau	TH	-
<b>11.45 Diwedd</b>			