

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

Date & time: Dydd Mercher 17 Mawrth 2021, 12.15-13.15  
Wednesday 17 March 2021, 12.15-13.15

Venue: via Zoom

*Dr Dai Lloyd AM –Chair (DL), Tristan Humphreys (TH) – Secretary/Coeliac UK, Claire Consantinou (CC), Ian Severn (IS), Dr Jill Swift (JS), Dr Ieuan H Davies (IHD), Alison Jones (AJ), Wayne Lewis (WS), Sian Evans (SE).*

Item
<p>Apologies for absence:</p> <p>Graham Phillips, Dr Richard Cousins, Dr Geraint Preest, Rebecca Bowen,</p>
<p>Minutes of last meeting</p> <p>a. Amendments and approval of the Minutes</p> <p>The minutes were approved without amendment</p> <p>b. Matters arising</p> <p>The group has received a reply to its letter (01/10/20) to Minister for Health and Social Care. The letter is supportive of the potential clinical pathway and states that officials would be 'happy to meet with clinicians and representatives of Coeliac UK'.</p> <p>AJ queried what form this pathway might take e.g how holistic would it be? Would it encompass pre-diagnosis, diagnosis and management? TH explained that as he saw it this was entirely open for discussion but that there were some good examples such as the work of the Modernising Patient Pathways Programme in Scotland. This took an all encompassing approach and has been tested across four health boards with a view to national rollout. IHD agreed that an all encompassing approach would be preferable. He also raised the importance of having a realistic time frame and ensuring children were a part of that. It was felt it should also address equity of access as well.</p>
<p>Impact of Covid</p> <p>a. Oral update: Endoscopy backlog</p> <p>TH laid out some of the impacts of Covid on endoscopy services across the UK. Essentially the story is much the same across the nations with Covid having badly effected waiting times to endoscopy. In particular in Wales this has hampered what was very welcome progress up until that point.</p> <p>JS updated on the situation facing adult endoscopy services in Cardiff. During the first wave, the service was primarily carrying out cancer work with routine, and even urgents put on hold. The service is making some progress. Turnaround times, especially for upper GI endoscopy is still a problem because it's considered an aerosol generating procedure. Theatres have to allow half an hour after finishing a patient before they can be cleaned and another patient brought in and as such are impacted more than colonoscopy. The service is running two rooms and alternating patients between with capacity down to about 60-70% of what would normally be being done on a list. In terms of Cardiff, all cancer patients are now being seen as well as urgents and bringing through the routines. Now working every weekend with insourcing</p>

teams coming in from Cardiff to move forward. Some outsourcing lists are still happening at SPIRE hospital as well. Things are improving and signs are positive but there is still quite an impact on waiting times, which are much, much longer than would be hoped. These are circa several months for routine endoscopy, and even some of the urgents however suspected coeliac patients tend to be put through as urgent, especially if they're symptomatic. The BSG guidelines for coeliac disease have been adopted and the service is working to those. Its very much the same as the children's guidelines currently - If a patient is under 45, doesn't have any other worrying symptoms that seem to be related to coeliac disease and a TTG that is of more than 10 times normal (which is 100 in Cardiff), then they can have an HLA and the EMAS as is done in children and no biopsy at all. Patients going down this route are seen by a dietitian for dietetic advice and will be offered a biopsy and a challenge later if they want.

IHD then provided an update on childrens service. Things haven't changed dramatically since the last meeting (07/12/20). It's not much worse, it's not a lot better. It's quite difficult to tease out who's waiting for an endoscopy for coeliac and who's waiting one for one for other potential diseases, but between IHD and Dr. Cosgrove in Swansea (who is doing this work when an endoscopy is indicated to try and diagnose and confirm coeliac disease) probably have about 30 to 40 children waiting. Some of these have been waiting for a significant time and the service has elected to treat some as if they have coeliac disease in the meantime, and get them on a gluten challenge six to eight weeks beforehand. Catching up post pandemic is going to be very challenging as there are basically three gastroenterologists currently covering this work. This will rise to 4 thanks to new health board funding but endoscopy resources remain stretched.

#### Gluten Free Prescribing

##### a. Update on situation in rest of the UK

TH explained that he had taken over as prescribing policy lead for the charity UK wide and provided an update on the current context. Not much has changed since the last CPG meeting (07/12/20). There have been a number of CCG mergers and now down to c.135 across England. Roughly 60% of CCGs are still prescribing bread and flour mixes with others having restricted further but what that looks like in practice depends CCG by CCG. Northamptonshire CCG is currently reviewing its pharmacy led prescribing scheme, which is funded by NHS England but administered by the CCG. The funding for that ran out in September but following concerns raised by Coeliac UK and others, it was extended to March subject to consultation. That consultation has now opened and the funding further extended to June to take account of consultation results. Coeliac UK will be submitting a response on behalf of the community in Northamptonshire and will be encouraging members to have their say too. Beyond this, the only other development is early discussion around possible reform of the health service in England.

##### b. Oral update on ACBS list

TH has spoken with contacts in the nations and as it stands there is no administrative process in either Northern Ireland or Scotland for approval of new products. Perhaps more importantly, commercial contacts raised concerns that product reformulations were not captured as result of this. Essentially, the Coeliac UK prescribable products list is being used in place of the old ACBS list. The charity was not previously conscious of that. From discussions, TH suggested there was a desire for a more sustainable long term approach and one that might be applied across the devolved nations. AJ concurred and felt this was an increasing issue in Wales. It was suggested this is something that should be looked at by any future group.

Action: TH to add to agenda of future CPG meeting

Updates from Coeliac UK

a. Awareness Week

Awareness Week was due to focus on diagnosis in children last year however this was postponed due to the pandemic. It was then due to run in this year's Awareness Week instead however having spoken to its Health Advisory Committee and various other partners, Coeliac UK took felt it wasn't an appropriate time to be driving people towards primary care and towards healthcare professionals more broadly. Therefore that piece of work around childhood and diagnosis has now been pushed back to September. Awareness Week will instead have a new focus. Working in tandem with the other sister organizations around the world through the Association Of European Coeliac Societies (AOECS), Coeliac UK will be raising awareness of coeliac disease using the hashtag #shinealightoncoeliac. This will be used across multiple sites and other coeliac societies. The campaign will be about highlighting real life stories and case studies, with messaging around moving from the dark into the light as covid restrictions begin to ease into the summer. This will also tie into the charity's fundraising challenge focus planned for June. Awareness Week runs 10-16<sup>th</sup> May.

b. APPG, APG & CPG plans

TH also laid out plans for the charity to establish a CPG (Scotland), APG (Northern Ireland) and APPG (Westminster) in the coming year.

Future of the group

a. Legacy report

TH presented the draft report to the group. The group requested a change of format with more clarity on headings and TH agreed to amend accordingly and submit this to the table office.

b. Thanks

TH thanked the group for their excellent contributions over the parliament and noted that the CPG was being used as a model for how the charity engages with policy makers across the UK. In particular TH wanted to thank DL for chairing the group and being a champion for the coeliac community in Wales. DL thanked the group for their efforts and expressed his appreciation for having been able to share such valuable contributions and meaningful work.

Action: TH to amend legacy report and submit to the table office along with minutes of the meeting

AOB

CC and colleagues have been shortlisted for the patient safety awards for their gluten free education video under the patient engagement category. They have produced and evaluation and are keen to share this with others to help inform the patient pathway development. TH congratulated the team and welcomed the opportunity to share good practice.

Action: CC to share link to education video with TH

<b>Action</b>	<b>Member responsible</b>
Add to ACBS of future CPG meeting	TH
Amend legacy report and submit to the table office along with minutes of the meeting	TH
Share link to education video with TH	CC