

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

Date & time: Nos Fawrth 19 Mehefin 2018, 18.00-19.30  
Tuesday 19 June 2018, 18.00-19.30  
Venue: Ystafell Gynadledda C, Tŷ Hywel.  
Conference Room C, Ty Hywel

No.	Item
1	<p><b>Apologies for absence</b></p> <p>Graham Phillips, Huw Jenkins, Jill Swift, Simon Scourfield, Henry Wilkins, Heather Stephens, Dr Vivek Goel, Huw Jenkins, Simon Thomas, AM, Llyr Gruffydd, AM.</p>
2	<p>Minutes of last meeting</p> <p>a. Amendments and approval of the Minutes</p> <p>The minutes were approved.</p> <p>b. Matters arising</p> <p>All matters arising were included in the agenda.</p>
3	<p>Additional Learning Needs Act(Wales)</p> <p>a. Update (Tristan Humphreys)</p> <p>Tristan Humphreys (TH) provided an overview of progress on the Additional Learning Needs Act 2018. It became law in January and the focus has now moved towards secondary legislation and the Code of Practice. We are concerned that their appears to be a desire from Welsh Govt to proceed with an unamended version of the code which as it stands threatens to make understanding and implementation of the Act more, not less, confusing with regards medical conditions.</p> <p>Coeliac UK have taken over coordinating the alliance following the loss of Sara Moran (formerly of Diabetes UK) to Lynn Neagle, AM's office. Coeliac UK will be hosting a meeting of all alliance members next month to prepare a response in anticipation of consultation in the autumn. Documents the alliance have seen suggest that there is still a limited understanding of how the law applies to children with medical conditions, particularly with regard to the application of the Equality act.</p> <p>The group will also look at legacy work and how they might put in place something via the Assembly to ensure implementation of the Act and care in schools more generally is properly monitored and scrutinised.</p> <p><b>ACTION: TH to lead meeting of the alliance and provide further update on this work at the next meeting.</b></p>
4	Prescriptions

a. Update on progress of Department of Health & Social Care Task & Finish group and new regulations (Norma McGough)

Norma McGough (NMG) reminded the group of the Department of Health & Social Care's (DHSC) consultation decision from early this year to maintain support for gluten free prescribing but to limit it to bread and flour mix. Sarah Sleet (Chief Executive, Coeliac UK) & Norma McGough (Director of Policy, Research & Campaigns, Coeliac UK) were subsequently invited to sit on the Task & Finish group with a view to revising the GMC regulation and revising the Drug Tariff in line with the government decision in England.

- It is planned that there will be a consultation on the new regulation to be launched soon though no date as yet.
- The drug tariff has been revised to clearly define what constitutes bread and flour mix for the purposes of this and manufacturers of gluten free foods have been notified.
- There is currently no change for the rest of the UK and there are ways of reflecting different drug tariffs across the devolved nations.
- Intention is to have a revised drug tariff published by November this year in England.
- There is still wide variation in England in gluten free prescribing policies due to local policy development in the 207 Clinical Commissioning Groups (CCGs).
- Meanwhile Vale of York have CCG decided to abandon their Chip & Pin scheme and instead follow the DHSC position. Luton CCG have also adopted this.
- Coeliac UK wrote to all CCGs where the policy offered less than the provision recommended by the DHSC (1/3<sup>rd</sup> of CCGs) and asked them if they would review their policy in line with the DHSC position. Some have said they are awaiting the final regulation whilst others have said they are continuing with their policy. New consultations and policy changes to remove access to gluten free prescribing are still proceeding in England
- Coeliac UK is seeking meeting with the Health Minister.

b. Update on Hywel Dda Prescribing pilot (Alison Jones)

Alison Jones (AJ) provided an update on the progress of the Hywel Dda prescribing pilot scheme. Despite delays, it has now started (as of 8 June) and money has been uploaded on the e-cards of all recipients.

- 64% uptake – 194 approached/123 take up
- 90% uptake in those wanting to take part in the research project. Very positive sign though will be unable to interview all those that would like to be involved but direct communication is being planned.
- Started 8 June and cards loaded for 3 months. These will then be reloaded for a further 3 months in November and the project will close in December
- £1 per unit loaded to a plain mastercard. For example, as a guide a male adult would likely receive £18 per month, a middle aged female would receive £14 per month, children (depending on age and gender) would be entitled to £11, £13, £15 or £18 per month, elderly women £14 and elderly men £16.
- So far no one has complained about the amount of money provided and the response has been very positive. People welcome the

flexibility of the scheme and it can be used for staple food on the go. The scheme is about subsidising the diet rather than being overly prescriptive.

- AJ can run reports on how and where participants are spending their money and expects first proper data in September after first 3 months of credit.
- Receipts to be sent in at the end of the 6 months.
- Of 72 people that didn't take part, 3 have been excluded from the data due to mitigating circumstances. One because they own a gluten free bakery, one is going through chemotherapy and one was wrongly included in the original prescribing list.
- 72 questionnaires have been sent out to find out why people didn't take part with help from Coeliac UK Research Manager, Heidi Urwin.
- End of November, prescriptions will restart and then AJ will evaluate.
- AJ no longer plans to host evaluation events as this coincides with the Health Boards restructure so risk of feedback being about other things. Instead, AJ will be visiting surgeries and holding walk in sessions to give everyone the opportunity to feedback.
- Following these, AJ will submit a paper to Hywel Dda board, the Cross Party Group & the Chief Pharmacist for Wales who is very interested.
- By the end of November should have good sense of whether the scheme works or not but so far feedback has been very positive.
- A rough cost savings analysis with Public Health Wales estimated time saved by GPs/practice manager equated to c.£250,000 but detailed cost benefit analysis will be included in the evaluation.
- Savings on the cost of prescriptions alone on the other hand (750 on prescriptions in Hywel Dda but 1,050 with coeliac disease) would equal £33,000 even if those not currently receiving prescriptions took them up. This doesn't include out of pocket expenses involved in pharmacy prescribing so actual savings would likely be far greater.
- This is provisional data and still more work to be done but is promising.

#### c. Questions & discussion

There was a broad discussion amongst the group about the potential for savings under this model. It was also highlighted that there may be knock on benefit of patients having a clearer sense of the cost of prescriptions. For example AJ pointed to the example of a participant who was shocked by the cost of Juvella bread mix and so was now buying fresh gluten free bread from his local bakery instead. Patients are now also going to supermarkets and asking them to stock specific products.

TH asked about the breakdown of the data and when AJ might be able to see how different demographics are using the card. For example how do those in areas of high deprivation or rural areas use the card compared to those in the city. AJ assured the group this would all be covered in the evaluation though there is a challenge with regard to online shopping as you can't use more than one card to pay for shopping. Geraint Preest (GPr) suggested using a third party payment system such as paypal however as it

	<p>stands it is not possible to limit spending to gluten free products through such a mechanism. It was felt this could be addressed following the pilot however.</p> <p>Rhun ap Iorwerth (RaI) AM was keen to discuss the process for rollout should the scheme be deemed successful. RaI &amp; Dai Lloyd (DL) AM to look at pathways to roll out via Welsh Assembly E.g holding an enquiry through Health Committee (Chaired by DL) and putting something on the programme for the new year. RAI also suggested a possible bid for Welsh Government funding through 'Invest to Save'. A discussion was had around the resources required and AJ suggested they would look at probably band 3-4, 2 days a week to run the admin of the scheme if taken forward.</p> <p><b>ACTION: AJ to update the group on progress at next meeting.</b>  <b>ACTION: RaI &amp; DL to investigate process for rollout via the Assembly.</b></p>
5	<p>Informatica</p> <p>a. Outline of suggested next steps (TH/NMG)</p> <p>GPr gave an overview of the challenges facing Informatica, the software used in primary care with a potential to aid GP best practice in alerting them to patients who may have symptoms of coeliac disease. It's a great concept but not being used. It appears that the use of software in primary care is changing. EMIS has lost its contract for providing in practice systems and will likely be replaced by MicroTest &amp; Vision when the contract is awarded for Welsh GPs. Ideal situation would be for one of the software companies to take the Informatica concept on board and develop it within their own software. We should expect the new software options in place by the end of 2018. TH hopes to have a meeting with Simon Scourfield (NWIS) in the coming weeks and will address this with him.</p> <p>Healthcare Professional Support in Primary Care?</p> <p>TH suggested it may be time to look at alternative ways of engaging with health care professionals alongside this. NMG provided an overview of work Coeliac UK has been doing on this front in England. Coeliac UK have been attending RCGP training events and have had more than 100 GPs sign up for further email communication. Its very obvious that knowledge and experience of coeliac disease is very poor in primary care and clearly there is a need to bridge the gap. Coeliac UK have also been working to develop relationships with professional bodies so provide short, sharp training and CPD and patient management resources.</p> <p><b>ACTION: TH to meet with SS and report back at next meeting. CUK to build HCP support resources into business planning?</b></p>
6	<p>Wales Gluten Free Food Show</p> <p>a. Update on plans for 2018 (TH)</p> <ul style="list-style-type: none"> <li>• Event takes place on September 8th, 10am -4pm. Cardiff City Stadium. You can register here.</li> <li>• 610 tickets sold so far. 9 exhibitors confirmed. 8 tbc. (c.17)</li> </ul>

	<ul style="list-style-type: none"> <li>• Aiming for 25 and expect further confirmations and uptake following Coeliac UK food festival/AGM on Saturday as well as a couple of Food Innovation Wales events we're speaking at in the next month.</li> <li>• In terms of promotion we have a Ad in the Reading show programme, Facebook ads to start end of July, EXG and internal mailings and PR end of August. We also have possible advertising with Wales online as an option.</li> <li>• Anyone wishing to volunteer, please get in touch with Tristan.humphreys@coeliac.org.uk.</li> </ul> <p>Sian Evans highlighted that her gastroenterologist colleague was promoting the show at the bottom of their letters to patients. TH was very grateful for this. DL also suggested that RaI provide a quote for the press release and RaI agreed.</p> <p><b>ACTION: TH to follow up with RAI</b></p>
7	<p>Awareness Week</p> <p>a. Recap on activity in Wales</p> <p>Tristan Humphreys provided a brief overview of activity from Awareness Week in Wales.</p> <ul style="list-style-type: none"> <li>• Coeliac UK worked with the Welsh Assembly caterers, Charlton House, to switch the canteen to an exclusively gluten free menu for the entirety of the day on the 15<sup>th</sup> May. This was accompanied by an information stand manned by TH with information on coeliac disease, providing an opportunity to discuss further with Assembly members.</li> <li>• The Davage family were interviewed on Radio Cymru's Post cyntaf on the 15<sup>th</sup> May and DL spoke to Radio Cymru post prynhawn later that day.</li> <li>• Graham Philips was the special guest on Chris Jones' Swansea sound radio show on the same day.</li> <li>• DL also delivered a 90 second statement on Awareness Week in the Welsh Assembly and raised the issue of underdiagnosis in relation to bowel cancer in an assembly debate on the matter.</li> <li>• Finally, Coeliac UK member Yvonne Smith from Corwen was interviewed for the North Wales leader.</li> </ul> <p>Coeliac UK would like to put on record its thanks to all those that took part in Awareness Week activities.</p>
8	<p>AOB</p> <p>a. Endoscopies &amp; gastroenterological services in Wales.</p> <p>TH suggested the group may like to pick up on this at a future meeting in light of the recent debate in the Welsh Assembly around the issue with regard to bowel cancer. There appears to have been little movement with regards JAG accreditation since the group last looked at this.</p>

	<p>DL pointed out that his Health, Social Care &amp; Sport committee would be looking at the issue in 6 months time and this would be a good opportunity for Coeliac UK to submit a response. TH agreed to do so.</p> <p><b>ACTION: TH to add to next meeting agenda.</b></p> <p>b. Cross Party Group social/celebration</p> <p>TH asked whether the group might be interested in a Christmas party or some sort of reception to celebrate the work of the group. The group were positive and TH will look into it.</p> <p>c. Research Fund</p> <p>Norma updated the group on the launch of <a href="#">Coeliac UK's research fund</a> to mark the charity's 50<sup>th</sup> anniversary. There has been increasing research into the potential neurological conditions associated with late diagnosis coeliac disease and the impacts of Type 2 refractory coeliac disease which has very poor prognosis. The charity is increasingly emphasising the most serious forms of the condition. Coeliac UK are seeking to raise £5m for research by 2020.</p> <p>As part of this Coeliac UK have in partnership with Innovate UK secured £750,000 grant fund for innovation between research organisations and SMEs. The call closes 3<sup>rd</sup> September. TH has met with Food Industry Centre Wales about this and is very keen to encourage take up from within Wales.</p> <p>d. Brandview – Coeliac UK CDNS</p> <p>Coeliac UK monitor the cost of gluten free foods using Brandview data. With the entry of retailers like Lidl and Aldi into the gluten free market it will be interesting to monitor the impact on prices.</p>
9	<p>Dates for future meetings:</p> <p>TH &amp; Marcia Spooner to circulate a date to the group.</p>

## Action Points

Action	Assigned to
Update the group on progress of Care in School Alliance	TH
Meet with SS & report back at the next meeting	TH
Follow with RAI re quote for Wales GF Show press release	TH
Add Gastroenterological services discussion to agenda for next meeting	TH

Update the group on progress of Hywel Dda Pilot scheme at next meeting.	<b>AJ</b>
Investigate process for rollout via the Assembly	<b>RaI/DL</b>
Circulate date for next meeting	<b>MS/TH</b>