

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

Date & time: Nos Mercher 07 Mehefin 2017, 18.00-19.45
Tuesday 31 March 2017, 18.00-19.45
Venue: Ystafell Gynadledda C, Tŷ Hywel.
Conference Room C, Ty Hywel

Attendees: Dr Dai Lloyd AM (Chair), Tristan Humphreys (Secretary), Dr Geraint Preest, Graham Phillips, Dr Jill Swift, Marcia Spooner, Nick Ramsay AM.

No.	Item
1	<p>Apologies for absence</p> <p>Dr Huw Jenkins, Henry Wilkins, Rhun ap Iorwerth AM, Mike Hedges AM, Sian Evans, Alison Jones, Clare Constantinou, Norma McGough.</p>
2	<p>Minutes of last meeting</p> <p>Minutes were approved without amendments</p>
3	<p>Support for learners with medical needs</p> <p>a. PRESENTATION: Additional Learning Needs (Wales) Bill</p> <p>Sara Moran (Diabetes UK) was due to attend but due to low turnout it was felt it may be best to postpone until next meeting. Tristan Humphreys (TH) provided an update on the latest developments with the Additional Learning Needs (Wales) Bill. The Children Young People & Education Committee scrutiny report has now been published. Coeliac UK are pleased to see the committee have accepted recommendations from the Health in School's alliance verbal and written evidence. In particular the committee accepted the need to amend the definition of Additional Learning Needs so as to include medical conditions.</p> <p>There is some concern from Coeliac UK perspective that this definition might be aligned only to conditions accepted as a disability under the Equality Act (2010). This would potentially exclude coeliac disease and some other longterm, chronic conditions from inclusion in the bill. However the sense is that this is not the committee's intention and there should be space to clarify this at stage 2.</p> <p>Initially had been looking at passage of the Bill in the Autumn however this could be delayed due to Financial Resolution being delayed until later in the scrutiny process.</p> <p>Coeliac UK and partners have also submitted consultation on implementation of the bill.</p> <p>b. Update on Schools Guidance</p> <p>Alun Davies AM, Minister for Lifelong Learning and Welsh Language, has written to all schools in Wales (view the letter here) to highlight the new Welsh Government schools guidance for Supporting Learners with Healthcare Needs. He has requested an update from all Local Authorities by the end of the term.</p>

	<p>c. Questions & discussion</p> <p>Dr Geraint Preest (GPr) highlighted issues of inconsistency of care for his daughter in school and a lack of understanding of coeliac disease, in particular citing the challenge regarding cookery lessons. TH agreed and explained variability of support was a major driver behind the need to secure a statutory duty and was a common issue for all those partners in the alliance. Food management is a big challenge for Coeliac UK but more broadly inclusivity is very important to all. It's important that schools take necessary steps to adapt activities to allow children to take part with the emphasis on including the child rather than simply excluding them from any activities deemed to pose risk. The above guidance has improved in this respect but remains voluntary and leaves ultimate decisions on whether a Health Care Plan is required in the hands of the Head Teacher. Without statutory backing, this does not abate the challenge of dealing with an obdurate Head Teacher. The inclusion of Medical Conditions within the Additional Learning Needs Bill would however deliver this.</p> <p>TH and Sara Moran to report back to group at next meeting</p>
4	<p>Gluten Freeevolution</p> <p>a. PRESENTATION: Introduction to the campaign</p> <p>Coeliac UK launched a new eating out campaign in the Senedd to coincide with Awareness Week (8-14th May). The 'Gluten Freeevolution' focussed on increasing availability of gluten free foods, particularly on the go. A range of resources are available for caterers including a new catering film and food guidance. Supporters also encouraged to use campaign postcards to encourage businesses to provide gluten free products.</p> <p>b. Awareness Week and Senedd activities</p> <p>The campaign was launched in the Welsh Assembly Canteen with a themed gluten free menu on offer to Assembly Members and staff throughout the day alongside an information stand for those wanting to find out more. Dr Dai Lloyd AM also submitted a Written Question to the Health Minister which prompted a supportive statement on gluten free prescribing.</p> <p>c. Questions and discussion</p> <p>A discussion was had around the danger of cross contamination and ensuring that where companies were advertising gluten free, they must understand the importance of proper procedures to mitigate this. The example was raised of restaurants not realising the need to change the oil in deep fat fryers. GPr was concerned that many are going to the opposite extreme with staff unwilling to vouch for the gluten free food just to 'play it safe'. TH emphasised the importance of proper communication both within the company to staff and crucially to the customer. It's not enough to just have someone in head office that understands, serving staff need to be made aware so they can answer questions or at least identify a colleague who can. Just providing a large list of ingredients without explanation is not enough. Providing gluten free foods properly doesn't have to be arduous and many companies do it very well.</p> <p>A general discussion was had regarding the rate of diagnosis of coeliac disease. TH explained the current diagnosis rate in Wales is 22% and the average time for a diagnosis is 13 years. This not only leads to unnecessary</p>

	<p>suffering for the person concerned but also leads to wasted NHS resources. This issue led to the launch of Coeliac UK's 'Is it Coeliac Disease?' campaign in 2015 aimed at raising awareness of the condition and improving diagnosis rates. GPr explained that this was very important as undiagnosed, untreated coeliac disease can lead to far greater chances of developing other conditions such as osteoporosis. This led to a discussion of the Informatica coeliac module.</p>
5	<p>Informatica</p> <p>a. Update on progress (NMG/TH)</p> <p>GPr provided a background on the software explaining the software tool is intended to aid GPs in the identification of potential cases of coeliac disease. Progress has been made and the software was rolled out in early 2016 however further work is required to ensure GPs are aware of it and know how to properly use it. TH added that efforts were being made to get permission to collect data centrally that would allow for monitoring the software's impact.</p> <p>TH updated the group on efforts to get DQS approval for the collection of said data stating that the relevant DQS meeting had again been delayed until the end of June. TH is seeking to meet with Simon Scourfield (NHS Wales Informatics Service) in advance of this and will report back to the group at the next meeting.</p> <p>GPr suggested protected learning sessions could be used to promote the software to GPs. TH agreed to take this forward.</p> <p>TH to approach Local Health Boards about use of protected learning sessions TH to meet with Simon Scourfield from NHS Wales Informatics Service TH to report back to group at next meeting</p>
6	<p>Prescriptions</p> <p>a. Update on NHS England consultation (TH)</p> <p>TH provided an update on prescribing in England.</p> <p>Over the past 18 months a significant number of Clinical Commissioning Groups (CCG) in England have limited or withdrawn provision of gluten free prescriptions in their area. Shortly after the last meeting (21.03.17), NHS England launched a consultation on gluten free prescribing. This proposed 3 options;</p> <ol style="list-style-type: none"> 1) make no change to existing system, allowing GPs to continue to prescribe in line with their local CCG prescribing policies 2) To remove all gluten free foods from the list of prescribable products. Under this option no gluten free foods would be available on prescription in primary care. 3) To only allow the prescribing of certain gluten free foods (e.g. bread and flour) in primary care. <p>Coeliac UK have responded to this consultation and this is available in full on the website. The charity has also released a press release and contacted all</p>

	<p>members, group organisers and campaigners to let them know whilst being clear this effects England only.</p> <p>Coeliac UK has opposed any plans to add gluten free foods to schedule 1 (option 2) and has argued in favour of GPs being able to exercise clinical judgement to support patients where necessary and in particular to support vulnerable patients due to the inequality issues around access to gluten free food in retail.</p> <p>The charity has also argued for the revision of the gluten free products listed based on competitive procurement to produce a shortened list of products that will provide cost efficiencies to the NHS.</p> <p>Hywel Dda Pilot</p> <p>After a brief delay, the Hywel Dda gluten free prescribing scheme is set to roll out in Aug/Sept. Alison Jones (AJ) has also received research funding so as to support a robust evaluation. She will present on this at the next meeting.</p> <p>b. Questions & discussion</p> <p>Alison Jones and Tristan Humphreys to meet in advance of the roll out of the Hywel Dda prescribing scheme Alison Jones to present on Hywel Dda prescribing scheme at the next meeting</p>
7	<p>AOB</p> <p>a. Gluten Free Food Show update (TH)</p> <p>The inaugural Wales Gluten Free Food Show will take place on 28 October from 10-4 at the Radisson Blu in Cardiff.</p> <p>So far 18 companies have been confirmed with 6 stands remaining. Headline sponsors are Genius and Prima Foods and other attendees are as follows: Welsh Hills, Schar, Tesco, Natures path, Monty’s Brewery, Wadworth, Glebe farm, Warburtons, Voakes, Juvela, Bfree, Green Sisters, Nutribrex, GOSH, Glutafin, Venice bakery.</p> <p>Fringe events will also be taking place on the day including dietetic clinics, research presentations and a panel debate.</p> <p>A bilingual promotional flyer has been produced and registration for the event is now live. TH invited members to join him on the day.</p> <p>Dr Jill Swift (JS) offered to promote the event in her clinics.</p> <p>TH to post leaflets to JS</p>
8	<p>Date of Next Meeting:</p> <p>6pm, 26 September</p>

Action Points

Action	Assigned to
Report back on progress of ALN Bill at next meeting	TH
Approach Local Health Boards about use of protected learning sessions	TH
Meet with Simon Scourfield (NHS Wales Informatics service)	TH
Report back on DQS committee decision	TH
Post leaflets pack to Jill Swift	TH
Hywel Dda Prescribing Scheme meeting	AJ/TH/NMG
Presentation on Hywel Dda Prescribing Scheme	AJ