

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

Date & time: Tuesday, 4th May, 12:35-13:25
Venue: Zoom

Attendees: Rhun ap Iorwerth – Chair (RaI), Tristan Humphreys – Secretary/Coeliac UK (TH), Sian Evans (SE), Heledd Roberts, Gwawr James (GJ), Dr Jill Swift (JS), Claire Constantinou (CC), Fiona Newsome (FN)

No.	Item
1	<p>Apologies for absence:</p> <p>Dr Ieuan Davies, Alison Jones (AJ), Dr Richard Cousins, Llyr Gruffydd, Rebecca Bowen</p>
2	<p>Minutes of last meeting</p> <p>a. Amendments and approval of the Minutes</p> <p>RaI asked if someone could approve the accuracy of the Minutes and mentioned that there needs to be a process for when no one was in attendance at the previous meeting. RaI acknowledged the Minutes were accurate. TH to circulate following the meeting.</p> <p>b. Matters arising</p> <p>CC updated the group on efforts to better understand coeliac disease (CD) dietetic services across Wales. CC has produced a survey an anonymous survey and shared with dietitians in each health board (HB). So far, seven responses have been recieved.</p> <p>The survey comprised of the following questions:</p> <ul style="list-style-type: none"> - How are referrals for newly diagnosed patients with coeliac disease (CD) received in your service? - Are newly diagnosed patients in your HB offered an appointment with the dietitian? - After an initial appointment for newly diagnosed patients, what follow up care will be offered within the service? - Where in your service are newly diagnosed CD patients seen? In primary or secondary care? - In your HB, are patients being seen by a specialist gastroenterologist dietitian? - Do patients in your HB routinely receive an annual review? If yes, where was the annual review carried out? - Are group education sessions for CD held? What educational or training methods do they use in their current pathway? - Does the HB have a clinical lead for CD? - Do you have dedicated dietetic resource for gastroenterology services? Do you have dedicated dietetic resource for CD?

	<p>- What whole time equivalent is allocated towards CD?</p> <p>Answers for the survey are documented in Excel and CC is happy to circulate this with members of this group. CC mentioned that there was a wide variation and little consistency in answers of what each HB is doing; only two out of the seven HBs have a clinical lead for CD. CC expressed the importance of a specialist dietitian seeing patients which is not necessarily possible in primary care services. CC welcomed the good practices and emphasised the importance of evaluation of services. There was a discussion on whether results should be sent after all HBs had responded; CC will send a reminder but close it by a certain date. TH suggested that the group looks into the pathway and pathway documentation in more detail at the next meeting.</p> <p>TH mentioned that Coeliac UK (CUK) are in the early stages of working on a funded project about diagnosis with a potential focus on Wales and hoped that the group could help identifying clinical champions. This will be added to the agenda for the next meeting. TH will keep the group updated on this process.</p>
3	<p>Verbal update from WLGA National Dietitian for Special Diets in Schools</p> <p>a. Free School meals rollout & WLGA Special diets work</p> <p>RaI introduced GJ and welcomes the introduction of free school meals across Wales, recognising that it was an exciting time but one that posed many challenges.</p> <p>GJ explained her role as a dietitian working in WLGA, specifically looking at special diets. GJ explained the challenges of there being limited national guidance for managing special diets in schools and some schools were unable to provide gluten free (GF). GJ expressed concern that they have no data for the amount of children on special diets in Wales; WLGA need this data to understand the impact for caterers and schools. The expectation is that there will be an increase in demand for special diets when free school meals are rolled out. There is anecdotal evidence that children with CD often bring a packed lunch due to issues of trust.</p> <p>WLGA aim to develop a national agreed upon guidance for managing special diets to integrate with the existing legislation. They want schools to be involved in this process having long term collaboration between national and local organisations. They want to ensure provision is equitable across Wales and look at the financial implications of providing special diets.</p> <p>WLGA aim to involve the schools, parents and children and have a school led approach, rather than relying solely on caterers as it has previously been in many schools. GJ highlighted the importance of sharing information and good practice. Additionally, it is important to have a whole school approach with guidance to cover the whole school day including breaks, school trips and cookery lessons. She further noted that school meals for special diets should be meeting the healthy meals guidelines in school regulations whilst also offering the child variety (E.g not simply offering a baked potato).</p> <p>GJ mentioned that they are looking at many options including registration for free primary school meals with an option for special diets or working with clinical dietitians across Wales to establish what support is currently provided and try to predict how many children have CD. GJ expressed the importance of</p>

	<p>mapping the training needs of caterers and whether the WLGA need to be providing all Wales training.</p> <p>RaI welcomed WLGA's approach of looking at the whole school and asked whether GJ felt she had the necessary input to ensure schools cope with special dietary. GJ said that they have been working closely with the Welsh government. GJ stressed the importance of getting data on the number of school children with special dietary needs.</p> <p>RaI suggested that the CPG should write to the education minister to express our excitement of universal school meals and the involvement of dietitians in WLGA to ensure that special dietary needs are met and ask what work is being done to find data on special diets before the introduction of this policy.</p> <p>CC wanted to know what the expectation of special diets was and the issue of multiple allergies. CC mentioned that trust can be an issue and questioned how to reassure parents and children that the right support will be there. RaI agreed and suggested adding a reference to inbuilt trust with parents and guardians in the letter to the minister.</p>
4	<p>Prescriptions</p> <p>a. Update on current prescribing policies across the UK</p> <p>TH provided an update on current gluten free prescribing policy across the UK.</p> <ul style="list-style-type: none"> - Northern Ireland has a traditional prescribing model accessed through the GP. There is a restructure of the health service ongoing however this is not thought to effect commisioning in the short term. - Scotland has a pharmacy led GF food service where prescriptions and annual reviews are managed by the pharmacy. - England has a patchwork postcode lottery; half of the 106 CCGs have withdrawn prescriptions in some form. Following an England wide review in 2017, the Department for Health and Social Care blacklisted all products bar bread and flour mix. However crucially it left it to CCGs to set more restrictive local policies where they felt it reflected the needs of their populations. Essetnially this set a ceiling of bread and flour mix but no floor. In July 2022, the 106 CCGs are due to be abolished in favour of 42 Intergrated Care Systems (ICSs) and there is concern this could trigger a further wave of policy restrictions; TH expressed frustration that many consultations have been treated as tick box exercises with eventual decisions often in conflict with the evidence submitted and the majority opinion of respondents. Coeliac UK is writing to DHSC about this issue. <p>b. Update on Hywel Dda Prescribing pilot and Wales rollout</p> <p>AJ was unfortunately able to attend due to illness so TH offered to provide a partial update. The plan was to finalise and roll out the top up card scheme across Hywel Dda HB by end of April 2022. TH explained that Welsh Government are keen on the project and would like to roll it out across Wales.</p>

	<p>AJ and Welsh Government have been in discussions with Coeliac to get the charity's views on the scheme and ensure its input from an early stage. There will be an expert implementation panel meeting from June and Coeliac UK will be sitting on the panel. TH highlighted the importance of setting a subsidy level that is appropriate, robust and transparent. He mentioned that there is a need to address challenges around online shopping and follow up support and these will be looked at at the meeting.</p> <p>TH emphasised that Welsh Government is planning a mixed model approach; the top-up card will run alongside traditional prescribing. This is critical as there has been some confusion amongst pharmacists as to the implications of the rollout. Coeliac UK have received a number of queries from members who had been wrongly informed their prescriptions would cease. Following discussion with the Deputy Chief Pharmacist, Welsh Government have committed to work with Community Pharmacy Wales to clarify this.</p> <p>c. Questions and discussion</p> <p>CC was pleased to hear that it was a mixed model approach as some patients prefer receiving prescriptions. CC asked how traditional prescribing would be protected. TH mentioned the scheme would be applied slightly differently to in Hywel Dda, where the top-up card is favoured by commissioners as the preferred approach.</p> <p>CC questioned whether gluten free prescriptions should be reviewed on a national basis and perhaps consider a model where dietitians or a specialist nurse could take on this responsibility rather than a GP. TH agreed a national approach was sensible and emphasised the importance of linking these points in with the broader pathway discussion.</p> <p>JW raised concerns about reducing contact with the GPs if there is a loss in prescribing. RaI emphasised the importance of follow up care. TH found the group's comments very reassuring as these points reflecting those Coeliac UK had raised with Welsh Government and were likely to form the basis for agenda of the implementation group.</p>
5	<p>Update on awareness Week & Children's Diagnosis Campaign</p> <p>a. Children's diagnosis campaign (April onwards)</p> <p>There was a soft launch of children's campaign which includes videos, case studies and animations which can be found on CUK's website. This will be running across the year.</p> <p>b. Awareness Week activity (9th-15th May)</p> <p>TH thanked RaI for the Statement of Opinion on Awareness Week in the Senedd to keep CD on the agenda and attract attention to ministers.</p> <p>TH explained that diagnosis is an ongoing issue; Awareness Week is an opportunity to highlight that.</p> <p>TH gave an update on CUK's fundraising challenges that are linked to 1 in 100 (the number of people who have coeliac disease across the UK); there have been some impressive challenges and these case studies will be shared throughout the year.</p>

	<p>There has also been a range of parliamentary engagement focussing on diagnosis including:</p> <ul style="list-style-type: none"> • Senedd Cymru: <ul style="list-style-type: none"> ○ Statement of Opinion • Scottish Parliament: <ul style="list-style-type: none"> ○ Motion to Parliament ○ Written Questions • Houses of Parliament <ul style="list-style-type: none"> ○ Parliamentary Questions ○ Diagnosis roundtable (postponed until July 7th) • Northern Ireland Assembly <ul style="list-style-type: none"> ○ APG recruitment emails to target MLAs. <p>RaI welcomed the developments and work on diagnosis.</p>
6	<p>AOB</p> <p>CC does not have a copy of the previous Minutes. TH mentioned that they are on the CPG website too but said he would recirculate the last Minutes.</p> <p>(UPDATE: The CPG webpage has the wrong set of minutes for October 2021. TH has contacted the table office to ask for this to be amended)</p>
8	<p>Dates for future meetings</p> <p>The next meeting will take place Autumn 2022, date to be confirmed.</p>

Actions	Member
Circulate results of dietetic services survey	CC
Circulate presentation about Free School Meals and Special Diets	GJ
Circulate Minutes from previous CPG meeting	TH
Draft letter to the Minister for Education about free school meals and special diets provision	TH