

Annual report & Financial Statement 2018-19

CROSS PARTY GROUP ON COELIAC DISEASE AND
DERMATITIS HERPETIFORMIS

Chair: Dr Dai Lloyd AM
Secretary: Tristan Humphreys

16 September 2019

1. Group membership and office holders

Chair:

Dr Dai Lloyd AM

Secretary:

Tristan Humphreys – Lead in Wales, Coeliac UK

Members:

Julie Morgan AM

Mark Isherwood AM

Mike Hedges AM

Nick Ramsay AM

Rhun Ap Iorwerth AM

Alison Jones	Clinical Lead Prescribing Support Dietitian, Hywel Dda Health Board
Chris Jones	Cardiff & East Wales Local Group
Claire Constantinou	Operational Lead Dietician, University Hospital of Wales
Dr Geraint Preest	GP & Primary Care Editor at BMJ on Examination
Graham Phillips	Swansea Local Voluntary Support Group
Henry Wilkins	Carmarthen Local Voluntary Support Group
Ian Severn	Membership Officer, Cardiff Coeliac Group
Sian Evans	Paediatric Dietitian, University & Hospital of Wales
Dr Jill Swift	Consultant Gastroenterologist, Llandough Hospital, Cardiff
Norma McGough	Director of Policy Research & Campaigns, Coeliac UK
Simon Scourfield	Operations Management Lead, NHS Wales Informatics Service
Dr Vivek Goel	Consultant Gastroenterologist, Spire Cardiff Hospital

2. Previous Group Meetings since the last AGM.

Meeting 1.

Meeting date: 27/11/2018

Attendees: Chair - Dr Dai Lloyd AM (DL), Secretary - Tristan Humphreys (TH), Norma McGough (NMG), Graham Philipps, Sian Evans, Claire Constantinou (CC), Alison Jones (AJ), Mark Isherwood AM.

Summary of issues discussed:

- **Additional Learning Needs and Education Tribunal Act (Wales) –** TH provided an update on progress regarding the above act. [A consultation on the draft code](#) will be launched in December 2018 with a closing date of March 22nd 2019. The Care in Schools Alliance (CISA) will be coordinating a joint response.
- **Prescriptions in England –** NMG provided an update on the situation regarding gluten free prescribing in England where prescribable products are now [limited to bread and flour mixes](#). Some concerns were raised regarding the impact this may have on available products in Wales as the [Advisory Committee on Borderline Substances \(ACBS\)](#) list is currently used here and will no longer be comprehensive.
- **Hywel Dda prescribing pilot-** AJ gave an update on the Hywel Dda top-up card prescribing scheme which has now come to an end. 194 people were originally approached across nine demographically representative practices in Carmarthenshire, Pembrokeshire and Ceredigion with 123 taking part (64%) in the top up card scheme. Feedback has been positive and the 104 of the participants have opted to stay on the scheme. A full report will be presented to the group in 2019.
- **Wales Gluten Free Food Show –** The Wales Gluten Free Food Show took place on 8th September at the Cardiff City Stadium. The event proved a great success with more than 1400 people attending. TH thanked all those that took part and volunteered their time on the day.

Meeting 2.

Meeting date: 19 March 2019

Attendees: Dr Dai Lloyd AM –Chair (DL), Tristan Humphreys – Secretary/Coeliac UK (TH), Alison Jones (AJ), Claire (CC), Dr Geraint Preest (GPr), Ian Severn, (IS), Jenny Pugh-Jones (JPJ), *Norma McGough (NMG), Rhun ap Iorwerth AM (RAI) *Ruth Passmore (RP), Sian Evans (SE) *Joining by Skype

Summary of issues discussed:

- **Hywel Dda prescribing scheme-** Alison Jones presented an overview of the Hywel Dda Gluten Free Prescribing Scheme. The Pilot ran from June to December 2018. Instead of Gluten Free food on regular prescriptions participants were given a pre-paid card, loaded quarterly with funds to cover the cost difference of Gluten free and gluten containing equivalents when purchased. A service evaluation via questionnaire was undertaken in November and December 2018. A lengthy discussion was had about the scheme. The group commended AJ on her hard work and look forward to hearing more at the next meeting. Further details can be found in the full minutes of the meeting.
- **ACBS list-** TH provided an update from the Lead in Scotland (Coeliac UK) regarding the ACBS list; There is no Scottish link now to the ACBS list. They instead now have all prescribable gluten-free food products listed in the Scottish Drug Tariff instead. AJ mentioned this is also being looked by the All Wales Medicines Strategy Group (AWMSG) and there is scope for crossworking with Scotland.

Meeting 3

Meeting date: 11 June 2019

Attendees: Dr Dai Lloyd AM –Chair (DL), Tristan Humphreys – Secretary/Coeliac UK (TH), Marcia Spooner, Claire Constantinou (CC), Ian Severn (IS), Dr Jill Swift (JS).

Summary of issues discussed:

- **Hywel dda prescribing pilot:** TH provided an oral update on the evaluation of the pilot scheme. The group is awaiting the full evaluation report. TH is due to meet with representative to discuss further roll out across the health board and a full discussion was added to the agenda for the next meeting.
- **Supporting learners with healthcare needs-** TH provided an update on progress regarding support for children with coeliac disease in schools. The Care in Schools Alliance (CISA) –chaired by Coeliac UK- has called on the Welsh Government to update [‘Supporting learners with healthcare needs \(2017\)’](#) guidance. There are plans for this to happen ahead of roll out of the ALN system in 2020. Additionally, Coeliac UK has been working with the Wales Local Government Association (WLGA) to develop best practice guidance for catering for special diets in schools.
- **Gluten free provision in hospitals-** A discussion was had regarding the challenges of securing good quality gluten free products in hospital. Despite seemingly good provision and processes on paper, there were concerns that this was not being matched at ward level. TH agreed to speak to colleagues in England about the situation over the border and report back at the next meeting. The group agreed to make this a priority over the coming year.
- **Endoscopy services-** TH updated the group regarding the recent [Health, Social Care & Sport committee report into endoscopy services](#) in Wales to which Coeliac UK had submitted evidence.
- **New Coeliac UK Chief Executive** – TH reported that Coeliac UK has a new [Chief Executive –Hilary Croft](#). She has a background in business having worked in leadership roles with Capgemini working companies such as Virgin Atlantic, Lego and Royal Mail. She also has knowledge and interest in the food and drink sector. More recently she was CEO of the Felix project (a charity that helps provide food to people suffering hunger and food poverty). She will be visiting Cardiff and a meeting was arranged with the Chair.

Meeting 4

Meeting date: 15 October 2019

Attendees: Dr Dai Lloyd AM –Chair (DL), Tristan Humphreys – Secretary/Colieac UK (TH), Rhun ap Iorwerth AM (RaI), Dr Geraint Preest (GPr), Sian Evans (SE), Ian Severn (IS).

Summary of issues discussed:

- **AGM & Election of officers-** The following officers were re-elected to their positions. Chair: Dr Dai Lloyd (nom. RaI. Sec. IS). Secretary: Tristan Humphreys (nom. DL. Sec. GPr).
- **Gluten Free Prescribing-** TH provided an update on gluten free prescribing in England; there has been no significant change since the Department of Health review limited available products in England to bread and flour mixes only. [CCG provision is broadly unchanged](#). TH also updated the group on the Hywel Dda prescribing scheme in West Wales where the health board have extended the existing pilot and still plan to roll out to all patients across Hywel Dda Health Board. An implementation group has been set up to discuss challenges around roll out with the next meeting to take place on November 6th. Coeliac UK will attend this and TH will report back to the group at the next meeting. Finally TH & colleagues at Coeliac UK have arranged to meet the Chief Pharmacist, Andrew Evans to discuss future plans for prescribing in Wales as well as the administration of the ACBS list.
- **Gluten free provision in hospitals-** A report was given regarding the situation in England and the upcoming [review into hospital standards](#). The group discussed challenges around the complaints process and IS shared his experience of sitting on a hospital nutrition group in England. The group agreed to address this again in the new year.
- **Supporting learners with healthcare needs-** The implementation of the [Additional Learning Needs framework](#) has now been delayed by a year to September 2021 and there is unlikely to be much progress regarding the Supporting learners with healthcare needs 2017 guidance. The Care in School Alliance will meet in the new year with a focus on engaging local authority education teams.

- **Wales Gluten Free Food Show** – [The Wales Gluten Free Food Show](#) will take place again on the 16th November from 10am-3pm. It will be the biggest yet with 25 exhibitors and an anticipated 1,500 people attending. There will be panel discussion chaired by DL & RaI offered to take part if available.
- **All Party Parliamentary Group (APPG) on Coeliac Disease** – IS asked what Coeliac UK was doing to set up an APPG in Westminster and similarly a CPG in Scotland. TH said this was something the charity was looking at and would report back at the next meeting.

3. Professional lobbyists, voluntary organisations and charities with whom the Group has met during the preceding year.

Coeliac UK.

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Apollo House,
Desborough Road,
High Wycombe.
Buckinghamshire.
HP11 2QW

Annual Financial Statement.

October 2019

Cross Party Group on Coeliac Disease and Dermatitis Herpetiformis.

Chair: Dai Lloyd AM

Secretary: Tristan Humphreys – Coeliac UK

Group's Expenses.	None.	£0.00
Costs of all goods.	No goods purchased.	£0.00
Benefits received by the group or individual Members from outside bodies.	No benefits received.	£0.00
Any secretariat or other support.	Secretariat provided by Coeliac UK	£0.00
Services provided to the Group such as hospitality.		
All refreshments paid for by Coeliac UK		
Date	Description and name of provider	Cost
27.11.18	Refreshments for CPG Meeting, Charlton House	£29.22
19.03.19	Refreshments for CPG Meeting, Charlton House	£34.92
11.06.19	Refreshments for CPG Meeting, Charlton House	£9.18
15.10.19	Refreshments for CPG Meeting, Charlton House	47.04
Total cost		£73.32