

# Annual report & Financial Statement 2016-17

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CROSS PARTY GROUP ON COELIAC DISEASE AND  
DERMATITIS HERPETIFORMIS

Chair: Dr Dai Lloyd AM  
Secretary: Tristan Humphreys

26 September 2017

## **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

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|---------------------|---|
| 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                    |
| Domonique Lardner   | Clwyd Local Group   |
| Dr Geraint Preest   | GP & Primary Care Editor at BMJ onExamination                               |
| Graham Phillips     | Swansea Local Voluntary Support Group                                       |
| Henry Wilkins       | Carmarthen Local Voluntary Support Group                                    |
| Dr Huw Jenkins      | Consultant<br>Paediatric Gastroenterologist, 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: 22/11/2016**

**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.

**Apologies:**

**Summary of issues discussed:**

- **Introduction and opening remarks from the chair-** DL welcomed attendees and introduced himself as the prospective Chair of the new Cross Party Group (CPG) on Coeliac Disease & DH and mentioned that he was the first Chair of the CPG in 2008 but was forced to step down in 2011 when he lost his seat. DL is also a Coeliac UK Governor. DL gave a brief overview of the Assembly's remit and invited members to introduce themselves in turn.
- **Coeliac UK Campaigns update** – NMG provided an update on the latest Coeliac UK campaigns including an overview of the success to date of the 'Is it Coeliac Disease?' diagnosis campaign. The Gluten Free Guarantee campaign is also to re-launch in January 2017 focussed at ensuring more convenience stores commit to stocking gluten free staple foods. Alongside this, Coeliac UK are also to launch an Eating Out during Awareness Week 2017.
- **Informatica-** The group discussed the roll of the Informatica coeliac software module for GPs across Wales. The impact on secondary care was considered including the potential geographical variance of diagnosis rates and the technological challenge posed by the inability to communicate between primary care computer systems and those in secondary care. Coeliac UK are to meet with NHS Wales Informatics to discuss ways of monitor said

impact.

- **Nice Quality Standard** – NMG highlighted the publication of a new NICE quality standard on coeliac disease and discussion were had around potentially developing a patient pathway. It was agreed this would be taken further at the next meeting.
- **Prescriptions-** NMG provided an update on the limiting of Gluten free prescriptions by many Clinical Commissioning groups in England and the work being done by Coeliac UK to try and protect existing provision. AJ explained she would be trailing a pre-paid card scheme in Hywel Dda as an alternative to the existing system in Wales.
- **Additional Learning Needs (Wales) Bill** – TH provided an update on the latest development regarding the Additional Learning Needs Bill and outlined Coeliac UK's desire to see medical needs included within it.

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## **Meeting 2.**

**Meeting date:** 31 March 2017

**Attendees:** Dr Dai Lloyd AM (Chair), Tristan Humphreys (Secretary), Alison Jones, Chris Jones, Claire Constantinou, Dr Geraint Preest, Dr Huw Jenkins, Dr Jill Swift, Mark Isherwood AM, Norma McGough, Rhun Ap Iorwerth AM, Sian Evans, Simon Scourfield

### **Summary of issues discussed:**

- **Prescriptions-** NMG provided an update on Coeliac UK's activity in response to withdrawal of provision of Gluten free prescriptions in Clinical Commissioning Groups across England. Alison Jones delivered a presentation on her upcoming prescribing pilot for Hywel Dda Health Board. A discussion was had about the merits of the scheme and the group welcomed its development whilst also calling for measures to limit misuse. Alison will update the group on progress at the next meeting.

- **Informatica-** Coeliac UK fed back on their meeting with NHS Wales Informatics (NWIS) service in September. It was felt that whilst the roll out had been successful from a technical point of view, more work was needed to promote the tool to GP Surgeries. Regarding measuring impact, Simon Scourfield explained that the data could be collected centrally on a daily basis provided the relevant NWIS committee agreed. Simon Scourfield agreed to work with Coeliac UK to secure the required permissions.
- **Patient Pathways-** Claire Constantinou gave a presentation on work that Cardiff & Vale Health Board have been doing on development of a proposed patient pathway. Norma McGough also fed back on a similar pathway that has been developed in Scotland. Discussion was had over the challenges facing service users and health care professionals and the group agreed to support Claire in the further development of her work.
- **Additional Learning Needs (Wales) Bill-** Tristan Humphreys updated the group on the launch of new Welsh Government guidance for children with medical needs in schools and the work Coeliac UK and partners in contributing to it. He explained that the charity was also calling for the inclusion of medical conditions in the Additional Learning Needs (Wales) Bill currently going through the Welsh Assembly as it was felt this would safeguard the rights of children with coeliac disease in school.
- **Awareness Week** – Tristan Humphreys laid out the plans for Coeliac Awareness Week including having a stand in the Welsh Assembly Canteen alongside a themed Gluten free menu. It was also suggested that Dai Lloyd could raise a question with the minister during the week.
- **Gluten Free Food Show** – Coeliac UK will host its inaugural All Wales Gluten Free Food Show in Cardiff on the 28<sup>th</sup> October. This will showcase 20 different companies and include cookery demos, beer tasting and expert talks and discussions. It is hoped 1,000 will attend and members were asked to save the date.

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### **Meeting 3**

**Meeting date:** 7 June 2017

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

#### **Summary of issues discussed:**

- **Additional Learning Needs (Wales) Bill-** Tristan Humphreys provided an update on the latest developments with the Additional Learning Needs (Wales) Bill. Coeliac UK welcomed the publication of the Children Young People and Education Committee report and noted they had adopted the central recommendation made by the charity and the Healthcare Conditions at School Alliance. A discussion was had around the variability of care in schools for children with coeliac disease. Dr Geraint Preest reflected on his daughter's experience and the lack of understanding of the condition from school staff. Tristan Humphreys highlighted variability and the need for inclusivity as crucial drivers for the charity's engagement with the Bill.
- **Gluten Freevolution-** Tristan Humphreys introduced Coeliac UK's new eating out campaign aimed at increasing provision of gluten free foods, particularly 'on the go'. Coeliac UK have produced a range of resources including a catering guide and animated films. The campaign was launched during coeliac Awareness Week (9-14<sup>th</sup> May) in the Senedd canteen with a themed gluten free menu and information stand for AMs wanting to find out more. Dr Dai Lloyd also submitted a written question to the Health Minister which prompted a supportive statement on gluten free prescribing.
- **Informatica-** A brief discussion was had on next steps for the Informatica coeliac module with Dr Geraint Preest suggesting Tristan Humphreys approach Local Health Boards so as to promote the software to GPs in their protecting learning time. Tristan Humphreys agreed to do this. The NHS Wales Informatics Service DQS panel are due to meet at the end of the month and Coeliac UK will be meeting Simon Scourfield in advance of this.

- **Prescriptions-** NHS England have launched a consultation on the future of gluten free prescribing. One option is to remove gluten free foods from the list of prescribable goods thus stopping gluten free prescribing in primary care. Coeliac UK have submitted a response, opposing this measure and calling for GPs to be enabled to exercise clinical discretion.
- **Gluten Free Food Show** – Registration for the Wales Gluten Free Food Show is now live and a promotional flyer has been produced. In total, 18 companies have booked stands and a further 6 spaces are still available.

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

**Coeliac UK.**

3<sup>rd</sup> Floor,  
Apollo House,  
Desborough Road,  
High Wycombe.  
Buckinghamshire.  
HP11 2QW



## Annual Financial Statement.

June 2017

Cross Party Group on Coeliac Disease and Dermatitis Herpetiformis.

**Chair:** Dai Lloyd AM

**Secretary:** Tristan Humphreys – Coeliac UK

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| <b>Group's Expenses.</b>   | None.  | £0.00   |
| <b>Costs of all goods.</b>   | No goods purchased.                          | £0.00   |
| <b>Benefits received by the group or individual Members from outside bodies.</b> | No benefits received.                        | £0.00   |
| <b>Any secretariat or other support.</b>   | Secretariat provided by Coeliac UK           | £0.00   |
| <b>Services provided to the Group such as hospitality.</b>                       |  |   |
| All refreshments paid for by Coeliac UK  |  |   |
| <b>Date</b>  | <b>Description and name of provider</b>      | <b>Cost</b>   |
| 22.11.16   | Refreshments for CPG Meeting, Charlton House | £32.28  |
| 31.03.17   | Refreshments for CPG Meeting, Charlton House | £21.42  |
| 07.06.17   | Refreshments for CPG Meeting, Charlton House | £21.42 (This was not charged due to an issue with refreshments) |
| <b>Total cost</b>  |  | <b>£53.70</b>   |