

Annual Report & Financial Statement 2014-15

CROSS PARTY GROUP ON COELIAC DISEASE AND
DERMATIS HERPETIFORMIS

Chair: Aled Roberts AM
Secretary: Jackie Radford

28th October 2015

1. Group membership and office holders

Chair:

Aled Roberts AM

Secretary:

Jackie Radford - Office of Aled Roberts

Members:

Jeff Cuthbert AM – (Labelling and eating out)

Llyr Gruffydd AM – (Gluten-free food prices)

Mike Hedges AM – (Gluten-free Guarantee (GfG) and prescriptions)

Mark Isherwood AM – (Research)

Rhun Ap Iorwerth AM – (Diagnosis and aftercare support)

Carole Carpenter – Clwyd Local Voluntary Support Group

Dr Dai Lloyd – Governor, Coeliac UK

Dr Geraint Preest - Primary Care Editor at BMJ on Examination.

Graham Phillips - Swansea Local Voluntary Support Group

Henry Wilkins – Carmarthen Local Voluntary Support Group

Dr Huw Jenkins - Consultant Paediatric Gastroenterologist, University & Hospital of Wales,

Jean Dowding - Cardiff Local Voluntary Support Group

Jill Swift – Consultant Gastroenterologist, Llandough Hospital, Cardiff

Dr Lindsay Morgan – Swansea Local Voluntary Support Group

Tristan Humphreys –Lead in Wales, Coeliac UK

2. Previous Group Meetings since the last AGM.

Meeting 1.

Meeting date: 4th November 2015

Attendees: Aled Roberts AM; Jackie Radford; Henry Wilkins (Carmarthen Group representative); Lindsay Morgan (Swansea Group representative); Jeff Cuthbert AM; Mike Hedges AM; Carol Carpenter (Clwyd Group representative); Jead Dowding (Cardiff Group representative); Lisa Bainbridge (Coeliac UK); Sarah Sleet (Coeliac UK); Rhun ap Iorwerth AM; Dr. Geraint Preest; Graham Philips (Swansea Group representative)]

Summary of issues discussed:

- **Update on progress of Gluten Free Guarantee (Gfg) initiative-** Chief Exec of Coeliac UK, Sarah Sleet, provided an update on its Gfg initiative. Much progress has been made but Coeliac UK will be continuing to review the campaign. Discussion was had around the challenge of getting smaller stores on board. Action: AMs present agreed to look into tabling a joint statement of Opinion encouraging smaller stores to increase gluten-free (GF) provision.
- **Enforcement and labelling** -Discussion of the enforcement of GF labelling in Wales including reference to available Coeliac UK accreditation and upcoming wide ranging impact of EU legislation coming into force on 14th December 2014. Action: Agreed to send letter to LHBs to check how they handle the listing of allergens in hospital and how they will adapt to changes post December 2014.
- **Improving availability-** Discussion re school provision, including training and responsibility. Discussion on standardisation of legislation in schools and hospitals and the investigation undertaken by the Assembly's Public Accounts Committee into Hospital Catering following the Wales Audit Report. Also considered opportunities

posed by the upcoming Public Health (Wales) Bill. Action: Coeliac UK to review proposals for potential amendments & produce Wales specific School Pack.

- **Diagnosis campaign-** Coeliac UK highlighted an upcoming public engagement campaign involving a self-assessment tool for coeliac disease based on the NICE guidelines on recognition and assessment. Action: Jackie Radford/Aled Roberts to put questions to Minister or Assembly Research Service re use of Infomatica in GP surgeries in Wales.
- **Areas of responsibility-** AMs agreed to take on specific areas of responsibility to be confirmed at the next meeting.

Meeting 2.

Meeting date: 24th February 2015

Attendees: Aled Roberts (Chair); Jackie Radford (Secretary); Jeff Cuthbert AM; Dr. Geraint Preest (GP Clinical Editor – BMJ onExamination); Dr. Jill Swift (Gastroenterologist – Cardiff & Vale UHB); Dr Lindsey Morgan (Swansea Group representative); Dr. Dai Lloyd (Swansea Group Representative); Norma McGough (Director Policy, Research & Campaigns- Coeliac UK); Lisa Bainbridge (Campaigns Manager- Coeliac UK); Tristan Humphreys (Lead in Wales- Coeliac UK); Jean Dowding (Cardiff group representative); Graham Phillips (Swansea Group Representative).

Summary of issues discussed:

- **Areas of responsibility-** The group confirmed the areas of responsibility for each Assembly Member on the group.
- **Letter to LHBs-** The text for the letter to LHBs was agreed. Action: Letter from Chair to be sent to all LHBs.
- **Regulation and Inspection Bill-** The new Regulation and Inspection (Wales) Bill could include reference to training for the provision of gluten free foods and it was agreed the Bill should be checked to see

what is included. Action: Jackie Radford to check Regulation and Inspection (Wales) Bill for issues affecting coeliac disease and gluten-free provision.

- **Pathway discussion paper-** Discussion of submitted paper and focus on potential lessons to be learnt from Scottish Gluten Free Food Service prescribing trial. Action: Coeliac UK & Jackie Radford to draft a letter to Health Minister regarding prescribing in Wales.
- **BMJ Audit software-** Introduction to new GP audit software being developed by BMJ to aid diagnosis of coeliac disease and potential for roll out in Wales.

Action: Dr Preest to report back at next meeting on necessary arrangements to secure roll out.

- **Diagnosis campaign-** Update from Coeliac UK on launch of new diagnosis campaign and agreement to host a launch event in the Senedd on the 12.05.15.

Action: Tristan Humphreys to liaise with Aled Roberts' office to arrange assembly launch event.

Meeting 3.

Meeting date: 12th May 2015

Attendees: Aled Roberts AM (Chair); Jackie Radford (Secretary); Jean Dowding (Cardiff Group representative); Tristan Humphreys (Lead in Wales – Coeliac UK); Norma McGough (Director Policy, Research & Campaigns- Coeliac UK); Geraint Preest (GP Clinical Editor – BMJ on Examination); Dr. Jill Swift (Gastroenterologist – Cardiff & Vale UHB); Ajay Kenth (New Customer Development Manager- BMJ); Henry Wilkins (Carmarthenshire Group representative); Bronwen Wilkins (Carmarthenshire Group representative); Dr Lindsey Morgan (Swansea Group representative); Rhun ap Iorwerth AM; Graham Phillips (Swansea Group representative); Mike hedges AM; Jeff Cuthbert AM; Bill Hyde (Carmarthenshire Group representative); Kathy Hyde (Carmarthenshire Group representative).

Summary of issues discussed:

- **Regulation and Inspection (Wales) bill-** Report from Jackie Radford on the Regulation and Inspection (Wales) bill and potential impacts on those with coeliac disease. Action: Jackie Radford to share research services' findings with Tristan Humphreys and liaise as to whether to further engage around the bill.
- **Letters to LHBS**
Two LHBS have responded to the Chair's earlier letter on allergen procedures. Action: Jackie Radford to forward LHB replies to Tristan Humphreys for further advice.
- **Update on BMJ software-** Ajay Kenth of the BMJ introduced the working software and updated the group on next steps regarding roll out. Action: Dr Jill Swift to make enquiries on behalf of the group and invite Dr Chris Jones or a suitable alternative to discuss potential impacts of software on secondary care.
- **Update on the launch of 'Is it coeliac disease? Campaign'-** Tristan Humphreys reported on the day's launch event and informed the group of plans to host a pop-up event in Cardiff city centre later in the year.
Action: Tristan Humphreys to liaise with Rhun Ap Iorwerth's office to ensure bilingual branding at the pop-up event.

Meeting 4.

Meeting date: 15th October 2015

Attendees: Aled Roberts AM (Chair); Jackie Radford (Secretary); Tristan Humphreys (Lead in Wales – Coeliac UK); Norma McGough (Director Policy, Research & Campaigns- Coeliac UK); Henry Wilkins (Carmarthenshire Group representative); Bronwen Wilkins (Carmarthenshire Group representative); Carol Carpenter (Clwyd Group representative); Heather Stephen (Clwyd Group representative).

Summary of issues discussed:

- **Annual General Meeting** -Officers were elected in keeping with CPG rules.
- **Sub-committee meeting with Dr John Green-** Report from the sub committee's meeting with Dr John Green regarding Gastroenterology services in Wales. Action: Jackie Radford to invite the Health Minister to the next CPG meeting to discuss issues raised
- **Gluten Free Prescribing-** Norma McGough and Tristan Humphreys presented a briefing on gluten-free prescribing in Wales. Action: Tristan Humphreys to report back on implications of the Public Health (Wales) Bill around pharmaceutical services and share Scottish Gluten Free Food Service review with the group.
- **BMJ Software-** Tristan Humphreys updated the group that the software is ready to launch in the coming months following a nationwide engagement with GPs.
- **Diagnosis campaign-** Report back from Tristan Humphreys on the latest figures from the campaign including plans for next year.
- **School Guidance-** All Wales guidance on 'access to education and support for children and young people with medical needs' is due for renewal at the end of the year. Action: Tristan Humphreys to liaise with the group on dates of the consultation.
- **Legacy report-** It was agreed the group should start work on a legacy report to ensure the work of the group could be built on post-election.

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

Coeliac UK.

3rd Floor,
Apollo House,
Desborough Road,
High Wycombe.
Buckinghamshire.
HP11 2QW

JAG.

JAG Central Office
Care Quality Improvement
Department
Royal College of Physicians
11 St Andrews Place
Regent's Park
London
NW1 4LE

BMJ

BMA House
Tavistock Square
London WC1H 9JR
United Kingdom

Annual Financial Statement.

28th October 2015

Cross Party Group on Coeliac Disease and Dermatitis Herpetiformis.

Chair: Aled Roberts AM

Secretary: Jackie Radford – Office of Aled Roberts AM

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.	No financial support received.	£0.00
Services provided to the Group such as hospitality.		
All refreshments paid for by Coeliac UK		
Date	Description and name of provider	Cost
12.05.15	Welsh Assembly Launch of 'Is it Coeliac Disease?' campaign	£172.50
Total cost		£172.50