

# Newsletter

## Editorial

*Michelle Selinger*

Here is something to read while we wait and wait for summer to arrive!- probably as long as you have been waiting for this latest newsletter!. Life seems to get busier and busier

The last few weeks have been particularly busy contacting the Herts Valleys CCG who have changed the formulary for our prescriptions without the due consultation that was promised with our local group. I have held publication of this newsletter until after our meeting with Paul Larkin, the Senior Locality Lead Pharmacist in the CCG on June 4th so we could report on the outcomes. Please see the report on pages 2-3. A big thanks goes to Tony Cartwright who has been spearheading this campaign. I know all our members appreciate the work and dedication you have put into fighting our corner

Since the last newsletter we held the AGM where we welcomed several new members and had an excellent talk from one of our members, Margret Morgan, on her role as governor of Coeliac UK. She also sought our feedback on the work of the charity. Margaret was highly entertaining and we had a very fruitful discussion. We also had another of our regular and chip nights at Godfreys which was well attended as was our meal at West Herts College in Watford.

A number of you kindly volunteered to help out at our stand at Intu in Watford for Awareness Week in May. Shoppers thought we were selling something so avoided our gaze, but we did help a number of people to take a questionnaire and then suggested they made a visit to their doctor, and we saw a number of coeliacs who may well join our group. A big thanks to all the volunteers and Ken from the Harrow branch.

Please continue to send me articles, recipes, food, restaurant and hotel reviews for the next issue to [glutenfreeherts@live.com](mailto:glutenfreeherts@live.com) or you can phone me on 07826 858533 with any ideas, questions or queries.

## Group Events 2016

Afternoon Tea July 17th 2:15pm	Henderson Hall Abbots Langley
Garden Party & Barbecue September 4th 1:30pm	Abbots Langley <b>Note new date</b>
Fish and Chip Supper September 26th 7:30pm	Godfreys, Harpenden
Themed Food Night October 27th 7pm	TBA
Meeting and Talk November 19th 2:45pm	Greenwood Hall
Christmas Dinner December 7th 6:30pm	West Herts College Watford

# News

## Vaccinations for coeliac patients - Did you know that they are essential?

*Tony Cartwright*

You may have been invited by your GP surgery to have an influenza vaccination and wondered whether to bother or not. You have more reason than most patients to consider vaccination. Scientific studies have shown that about one-third of coeliac patients suffer from splenic atrophy (where the spleen is shrunken). The spleen is a vital part of the immune system which fights off infection, so you may be more at risk. So if you get invited for a vaccination at your GP or get it offered in your usual pharmacy it would be sensible to accept. Pneumococcal infections lead to pneumonia, but there is a pneumococcal vaccine (sometimes called the pneumo vaccine), and you may only need to get this once. Ask your GP if it has not already been offered to you.

## Meeting of members in the Herts Valleys CCG area with Paul Larkin, Senior Locality Lead Pharmacist for the CCG, 4<sup>th</sup> June 2016

Paul Larkin made a PowerPoint presentation on the CCG's decision to restrict the prescribing of gluten-free foods in the Herts Valleys CCG area. The presentation was discussed by the members as each slide was presented. Key items from the discussion were as follows:

**Rationale for the restriction to 8 units/month:** This restriction was solely due to the CCG's need to save money on its drug budget.

**Consultation:** Paul Larkin apologised for the lack of any consultation with local patients who will be affected by the change. The CCG's Patient and Public Involvement Committee had been consulted and then the clinical commissioners in the CCG. There had also been no consultation with dietitians in the West Herts NHS Trust.

**Children and Students:** No consideration had been given to any special needs for children with coeliac disease or students in full-time education with limited financial means. The same allowance of 8 units/month would apply to children and students.

**Impact analysis of the restriction:** No analysis had been done of the impact of the restriction on patients on low income or with restricted mobility and thus less able to buy extra gluten-free foods on prescription. It

was acknowledged that the restriction could affect their dietary adherence and hence cause further illness and thus cost to the NHS.

**What should patients do if they cannot afford to buy more GF food from supermarkets?** Paul Larkin suggested that if particular patients have difficulty in being able to afford to purchase extra GF food in supermarkets to supplement the 8-unit allowance that they should contact their GP who had the ability to override the CCG guidance on the restriction. He would support this within the CCG if necessary.

**Review of the proposed formulary:** The current CCG formulary proposal had been drawn up by the pharmacists in the Pharmacy and Medicines Optimisation Unit and was restricted to a single supplier of fresh bread (Warburtons), long-life bread from Glutafin and Juvela, a single flour mix from Barkat, and pasta from Rizopia. This very restricted list was criticised by the members present; they wished to be able to order a wider range of products within their 8-unit allocation – for example to include crackers and rolls to meet their individual dietary needs as well as cereals. Many of the members particularly liked the NHS prescribable gluten free products which contained Codex Alimentarius GF wheat, which made it more palatable (supermarket "free from" products tended not to contain wheat, gluten or dairy ingredients). The need for prescription products to be available with added fibre/minerals and vitamins was also mentioned. Other members needed a wheat free/gluten free product because of their sensitivity to wheat. Paul Larkin agreed to review the formulary to provide more choice but asked for help from members of the group to do so. It was agreed to circulate a questionnaire to our members with a list of products with their NHS prices. Once responses had been received, and the results analysed the information would be sent to the CCG. Julia Pentelow from the West Herts NHS Trust said that the West Herts dietitians would also be pleased to advise on the proposed formulary.

**Annual monitoring of coeliac patients in Herts Valleys CCG area:** The CCG were proposing to mention the need for an annual review and tests in both the letter sent to coeliac patients and in the letter to GPs. There was no intention to ask GPs to send an annual reminder to patient along the lines

of the influenza vaccination reminder. Members present were asked how many now received an annual review and blood tests. Nine out of the 36 members currently receive an annual review and blood tests (25%).

#### **Information already sent out to GPs on prescribing:**

In the light of the review of the current proposals for the formulary Paul Lewis was asked to get the CCG to withdraw the information from their website and alert GP practices not to make any changes in their prescribing until the new formulary, patient information etc. had been produced. He agreed to pass on this request to the clinical commissioners in the CCG but could not promise that this would result in any action. He recommended that the South Herts Group write to Cameron Ward the Accountable Officer for the CCG.

#### **Other comments on assertions made in the presentation**

**Restriction of prescription GF products had been introduced by 'many other CCGs'.** In fact, 65% of the English CCGs are still following the National GF Prescribing Guidelines.

**Foods are not provided for other long-term conditions.** Coeliac disease is unique in that the only treatment is the strict avoidance of food containing wheat, rye or barley. Also the variable adherence of patients to the GF diet should not be used as a justification for restriction of prescribing – this would be likely to impair dietary adherence even further if some patients struggled to be able to afford the additional cost.

**Juvela and Glutafin flour mixes are considerably more expensive than supermarket flour mixes.** This is true, but they have been designed to be very easy to cook to provide a wide range of products. One member had tried out supermarket GF flour products mentioned in the presentation and had found them much more difficult to use, and the quality of food produced was inferior.

**A wide range of gluten-free products are available in supermarkets.** The CCG had already been advised by Coeliac UK that not all supermarket branches have a wide selection of GF foods. Smaller and budget supermarkets often have none. Paul Larkin was given copies of the two large published academic surveys from 2011 and 2015 on the availability of GF foods for purchase. The Herts Valleys CCG had not done any

independent survey of availability of GF foods for purchase from supermarkets in this area.

**Cost of gluten free foods:** A survey had been done by researchers from Sheffield and presented at the Coeliac UK Research Conference this year. This showed that the median extra cost of buying GF foods was over £8 per week in CCG areas where there was a restriction in GF prescribing or where no GF foods were allowed to be prescribed. Paul Larkin was given a copy of this poster presentation.

The new and current formulary has only a very restricted list of products. Coeliac UK had commented on it and it had now been agreed that the South Herts members would be consulted directly.

**PLEASE LOOK OUT FOR THE QUESTIONNAIRE WHICH WILL BE SENT TO YOU BY EMAIL AS AN ONLINE SURVEY, OR BY POST TO THOSE WITHOUT EMAIL.**

This is a unique opportunity for all those living in the Herts Valleys areas to have their say and will give you some chance of your favourite bread, flour mixes and pasta, at the very least, being on the formulary list for the region.

## Food to Go

*Helen Dunstan*

Marks and Spencer's have some very acceptable ready meals in their Gluten Free/ Made Without Wheat range if you're needing something quick and easy - Chicken Arrabbiata, Spaghetti Bolognese, Macaroni Cheese, Lasagne and Spaghetti Carbonara.

The Spaghetti Bolognese and Lasagne are particularly nice, priced at approx £3.50 - £4, to be found in the chilled ready meal section which also includes gluten free quiche, scotch eggs, sausage rolls and pork pies.





# Event reviews – picture gallery



## Dinner at West Herts College, Watford, May 2016



## Our Awareness Week stand at Intu Wat- ford, May 2016

# Eating out

## Locally

### Côte Brasserie, High Street, St Albans

Tony Cartwright

You may have seen a mention in *Crossed Grain* that the Côte chain of restaurants now has an improved gluten-free menu. We tried their restaurant in St Albans out recently and were very pleased. It is no exaggeration to say that the menu is impressive – I counted 8 starters, 5 light main dishes, 8 main meals of meat or fish, one chicken dish and various steaks and sauces. If you got that far, there were 6 desserts. The service was quick and friendly and there was a good choice of wine, beer etc. I had the Baked Crottin followed by the Breton Fish Stew. We have added it to our list of places to go back to.

### Burston Garden Centre

### North Orbital Road ,St Albans, AL2 2DS

Linda Walters

I recently went to Burston Garden Centre with my daughter. I'm coeliac and she is wheat free. Whilst there we decided to have a drink in their cafe. When looking at the menu, we were delighted to find they have gluten free bread readily available (just ask) and thoroughly enjoyed an impromptu bacon butty! We have returned twice since and enjoyed jacket potatoes and cakes. They have a gluten free menu displayed on the wall at the entrance to their cafe and we applaud them for making our choices so easy and stress free. Thank you to Burston and please give them a try everybody, and spread the word!

### Sanuk

### Little Heath Farm, Little Heath Lane, Potten End, Berkhamsted, HP4 2RY

Michelle Selinger

I lived in the village for 5 years before I discovered this hidden gem A lovely tea room with all home made cakes and at least three scrumptious gluten free offerings. Tea is served in china cups and pots and is very reasonably priced. Lunch is soup and they usually have GF bread. It is in the grounds of a lovely ramshackle garden centre that isn't part of a chain and has knowledgeable owners. All in all , a visit to the farm is a wonderful summer afternoon's treat.

## Zizis

*Samantha Neale*

Zizis in Watford or St Albans are wonderful for gluten free. They have a huge allergen menu with nice sized GF section and the gluten free pizza is amazing. Much better than pizza express (who give you a smaller one than everyone else, from the stock of gf frozen pizza bases, and charge you the same price as the non GF people). Zizis make their GF pizzas from scratch, which means they are deliciously the right consistency, just like a normal pizza should be. Thin, crispy round edges, the doughy base I've been missing. The zucca pizza is amazing, butternut squash, spinach and goats cheese with balsamic vinegar. The pizza comes out with a sticker on the side of the plate assuring you this is a non gluten ingredient containing pizza.

## London

**Honest Burgers, Various locations in London.**  
See [honestburgers.co.uk](http://honestburgers.co.uk) for nearest location

*Michelle Selinger*

I took Mia, my soon to be 7 year old granddaughter here on her first shopping trip to the West End for her birthday. Delicious burgers in a crisply toasted GF bun and the burgers and chips were all GF. One of the best burgers I've had. The most exciting part of Mia's day? As she told her other Grandma, she had tomato sauce UNDER her bun AND by her chips! I cant imagine she'll be that easy to please when she's 17 ...

**La Polenteria, 64 Old Crompton Street, London W1D 4UQ**

*Tony Cartwright*

You have gone up to London for shopping, an exhibition or whatever and wonder where you can go for a gluten-free meal. You would probably not think of going into an Italian restaurant as a first choice. But how about an Italian restaurant where every dish is gluten-free? This is La Polenteria. We ate in there on a Saturday lunch-time, we had booked (020 7434 3617) but there were some tables free when we arrived. The service was very friendly and it was not too expensive. I had the beef ravioli with pine nuts and raisins.

## Cotswolds

**Smiths of Bourton , Victoria Street, Bourton-on-the-Water, GL54 2BT**

*Michelle West*

This lovely teashop sells gluten free cakes. and is well worth visiting if you are ever in the Cotswolds



## China

*Mia Hartgrove*

My son who was 13 years old only two weeks before his 14 day school trip to four cities in China managed to sort his own food without getting ill at all. Before the trip I went to the school and had a face to face meeting with the teacher who was looking after my son's sub-group, but on the trip the teacher was not really available during meal times.

This was his verdict: "It was quite easy to order food in hotels and restaurants. I ordered food without any sauces on and peeled off any skins that had marinade on. It was very difficult to buy much in shops as either it was unpackaged or the labels were in Mandarin only."



# Recipes

## Clementine Cake

Valerie Allen

### Cake

300g clementines  
4 eggs  
140g caster sugar (plus a little to candy the clementines)  
150g ground almonds  
1tsp baking powder

### Mulled wine syrup

100g caster sugar  
150ml cold water  
50ml red wine  
1 stick cinnamon  
1 piece star anise  
1 orange (peel only)

### Cake

Cut 4 slices of clementine with a sharp knife & cook them in some caster sugar & a touch of water until softened. Take out slices and set aside for later. Boil the remaining whole clementines in water for 2 hours & then blend to a pulp. In a separate bowl whisk eggs & sugar together until white & frothy. Mix pulp with almonds & baking powder & fold into egg mix, Arrange the candied clementine slices on the bottom of a greased square baking tin. Pour cake mixture over the top

Bake at 160°C for 45 minutes and serve warm with a drizzle of mulled wine syrup and ice cream (serves 4)

### Mulled wine syrup

Add ingredients to a pan & bring to a simmer, dissolving sugar in the liquid- do not use a spoon to stir as this will crystallise the sugar. Reduce the liquid by half until the syrup coats the back of a spoon, Remove the orange peel, cinnamon & star anise. Chill well & the sauce will thicken.



## Chocolate Brownies

*These delicious Brownies were brought to the AGM but there's no name attached to the recipe .*

Makes about 15

3ozs (85g) GF plain flour  
1tbsp GF cocoa powder  
Good pinch of salt  
1tsp GF baking powder  
6ozs (170g) soft light brown sugar  
2ozs (55g) butter  
2tbsps water  
3.5ozs (100g) plain chocolate  
1tsp vanilla extract  
2 large eggs, beaten  
1oz (25g) chopped walnuts or raisins, etc. (optional)



Heat oven to gas mark 4/180°C and line a 7" x 11" (18cm x28cm) tin with baking paper. Sift flour, baking powder, salt and cocoa into a bowl. Put sugar, butter, water, chocolate and vanilla extract into a saucepan and heat gently until melted. Add the melted mixture to the flour mix, add eggs and beat until smooth. Add fruit or nuts at this stage, if desired. Pour into tin and cook for about 20 minutes until firm to the touch and slightly crusty on top. Leave the brownies to cool for 10 minutes then mark into squares. Cool completely before removing from tin.