

Newly and Recently Diagnosed Newsletter June 2013

Welcome

- Welcome to the meeting especially to those new and recently diagnosed members, their carers/supporters.
- For Fire Risk and insurance purposes would everyone please sign in?
- In the event of a fire alarm sounding please leave the building by the nearest fire exit and proceed to Albert Road, turn right and walk along to the small cul-de-sac where the register will be checked. Please do not return to the building until told to do so, nor leave the site until you have been checked off on the register.

Goodie Bags

- Tonight's 'goodie bag' contents are courtesy of Juvela, Warburtons, General Dietary, Seabrooke Crisps, Asda, Ugo Foods and DS.

Tonight's programme

- 7.15pm Registration
- 7.30pm Welcome and introductions Kathryn Robinson Head of Nutrition and Dietetics with The Royal Wolverhampton NHS Hospital Trust (New Cross Hospital)
- 7.45pm Coeliac Disease - what is Coeliac Disease
- 8.10 pm Refreshments and raffle tickets
- 8.30pm The gluten - free diet explained
- 8.45pm Question and answer session
- 9.05 pm News update, Vote of Thanks and raffle draw.

Wolverhampton Group Who's Who and What's What

- The group is run by volunteers under the auspices and guidance of Coeliac UK
- Running costs are met by fundraising, grants and donations, there is no financial assistance from CUK head office
- There is an AGM in January/February when officers and a committee are elected
- The group meets 5 times a year (4 general meetings and 1 for those newly and recently diagnosed)
- There are several social events:- skittles, Bakery Tours, Dinners etc) and we ask for payment in advance
- Alan Tunstall is Group organiser; Marion Burns is our Membership Secretary; Linda Young, Treasurer; and Barrie James, Lol Allen, Jill Darby, John Danby, Pam Picken and Ian Jenkins are committee members and Jeanette and Colin Babb act as fundraisers. However help is always welcome – as the say "many hands make light work".
- There are over 800 members allocated to the group either by CUK or people who choose to join the group but are not members of CUK. To help keep costs down we have a system where only those who choose to "join" the Wolverhampton group are contacted.
- Members are sent the annual report containing the events for the coming year at the beginning of January and will continue to receive annual updates providing they "sign up" to the group.
- Due to technical difficulties the e-mail newsletter distribution list has been suspended, the only other means of receiving information is from the CUK webpage www.coeliac.org.uk/wolverhampton or by attending the meetings, when you will receive a news update hand-out.

Wolverhampton Group Website and E-mail Address and News

- We are online and you can e-mail the group organiser at: wolverhampton@coeliac.org.uk
- Please be patient when anticipating a reply, remembering that this is a volunteer run service.

Social Events

- Christmas meal to be announced in September payment in full required to guarantee a place.
- If you only have one Christmas night out make it a gluten-free night out.

Coeliac UK's Campaign Network

- Are you passionate about raising awareness of coeliac disease and the gluten-free diet? CUK need committee campaigners to help them address the issues that matter to you.
- If you would like to get involved please email campaigns@coeliac.org.uk or call 01494 796114

Prescription Food

- Have you contacted the Food Manufacturers for samples of their products? Most have a telephone helpline to call.
- If you don't like something do try another product from another company - they do vary widely in quality, taste, texture etc. across the range.
- Have you been to see your GP to ask how they go about adding items to your prescription and how you get repeat prescriptions? Sometimes it's the receptionist who determines what you are allowed to order! Remember coeliac disease is a medical condition requiring a clinical decision.
- There are guidelines to help your GP determine the amounts to prescribe, you should have that in your CUK welcome pack or find it on the CUK website.
- But remember the allocation is at the discretion of the GP and depends on your compliance with other aspects of your diet. If you are not following a gluten-free diet then your doctor may have difficulty in prescribing gluten-free foods.
- Try and choose a pharmacy where there is a regular pharmacist who gets to know you and can help you.
- Ask for a pharmacy label on every item (good for stock rotation or if there is a problem with an item, no dispute on where you had it from, or when travelling abroad at Customs)

Meal/Ingredients Planner

- Why not use the template on the back page to help you plan meals or make appropriate ingredient changes to continue enjoying your favourite dishes to help you follow a gluten-free diet?

Professional Membership

- Why not try to encourage your GP or Pharmacist to join CUK as a professional member – it's free and they will receive information on all aspects of clinical research, patient care etc.

Osteoporosis (thinning of the bones)

- It's recommended that your risk of osteoporosis is assessed at diagnosis, and if you have certain 'risk factors' present you will be offered a DEXA scan. Your dietician will also check the amount of calcium in your diet at one of your early appointments. If you have any questions about the health of your bones please ask your healthcare professional.

Supermarkets

- All the supermarkets have Free-from ranges but you might have to scout around to find shops which stock other products, ask other Coeliac for advice. Sainsbury's are working with CUK to remove gluten from ready made products where it isn't an essential ingredient i.e. cottage pie etc.

Marks and Spencer's, Beatties, Starbucks, City Bar, Glutton's for Nourishment

- M&S do gluten-free individually wrapped choc-chip muffin in Café Revive.
- Beatties and Sainsbury's scrummy gluten-free Honeybuns in their own Restaurants.
- Starbucks have g-f sandwiches and cakes BUT get there early for the sandwiches.
- City Bar, King Street will make g-f sandwiches to order.

Eating Out

- City Bar, King Street; J D Wetherspoons, The Bluebrick, Lai –Do Chinese Birmingham New Road, Coseley; and Morrison's at Bilston have menus marked where dishes are suitable for coeliacs.
- Ask if the establishment has an allergy list – most large pub chains do.
- Fish and Chip shops check websites for details of gluten-free nights at Merchants Fish Bar in Bewdley and the Atlantic Fish Bar in Kingsbury and Chip Stop in Penn.

Children's Section – Young Coeliacs, Fun Food and Facts

- There is specific group for children under 16 see the CUK Young Wolverhampton website for details, or contact them at youngwolverhampton@coeliac.org.uk

Holidays

- Inform the airline, hotel in advance.
- Take some supplies with you as a precaution – some in the suitcase in the hold, some in hand luggage.
- Ask your GP for a letter explaining you are carrying food for medical purposes.
- The resource box has a copy of the travel guide containing appropriate foreign language phrases for gluten-free food.
- Try carrying dietary alert/information cards – available in European languages , for catering staff.

Gluten-free communion wafers

- We have a small supply of gluten-free wafers - they are in the resource box see Barrie.
- If you need to take a few - please do so until your Church can get some for you.
- There is also a letter to give to the vicar/priest/minister to explain the situation.

Meeting Dates 2013

- 18th September – Glutafin Cookery Demonstration
- 20th November – Tried & Tested evening – with celebrity judges

CUK Food and Drink Directory/Welcome Pack

- Think about joining CUK? You can join online or contact Coeliac UK on 0845 305 2060.
- You receive a copy of the Food and Drink directory a handy book for shopping etc., along with a quick reference gluten-free check list and a welcome pack full of useful information.
- The fees you pay to be a member of Coeliac UK helps in supporting work with the food sector to improve the supply of gluten free products, and the health-care sector to raise awareness of the condition and help people get diagnosed. It also helps to fund medical research into all aspects of the condition.

Alan Tunstall – Group Organiser 26th June 2013

Wolverhampton Voluntary Support Group
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Registered no. 3068044 Charity no. 1048167

Menu/ Ingredients Planner

Meal/Dish	Before diagnosis	After Diagnosis	Shopping/ prescription
Breakfast			
e.g. Poached Egg on toast	Poached egg on Warburtons wholemeal toast	Poached egg on gluten-free toast	Prescription bread
e.g. cornflakes and milk	Kelloggs	Eg Tesco Cornflakes	Tesco own brand cornflakes
Lunches			
tuna mayo sandwich on Mothers Pride white bread	Shop bought Sandwich	Home made sandwich on Gluten-free bread.	Prescription bread Tinned tuna and g-f mayo check directory
Main Meal			
Cottage pie	using e.g.Oxo cubes and flour to thicken	using Kallo stock cubes, gravy browning and cornflour to thicken	
Snacks/Treats			
Bourbon biscuits	McVities	TruFree Bourbon biscuits	Waitrose/Tesco