



Leicestershire Group Newsletter November 2016

Welcome to the latest newsletter from the Leicestershire Coeliac UK Voluntary Support Group. I would again like to extend many thanks to members who have given us a donation or stamps – they are much appreciated and we are very grateful.

Since the last newsletter we have had a members' evening where Cathy Steele told us about the new care pathway for coeliacs in our area, from diagnosis through to annual checks. This has been available during October for us to make comments. We don't yet have a date for the pathway to be implemented.

We have also been consulted on our views on stopping or reducing our gluten-free prescriptions. The final decision will be made at a board meeting of the CCGs in November, so we will let you know later in the month. Gluten-free prescribing has also been debated in the House of Commons.

David Mowat MP, the Parliamentary Under Secretary of State at the Department of Health said:

"The hon. Gentleman mentioned consultations. CCGs should not withdraw gluten-free products without a consultation. My understanding is that in all cases where that has happened, a consultation has taken place. If he can provide me with evidence of that not being so, I will follow up and take action. The information I have been given is that consultations should always have taken place."

"Finally, there is the issue of the postcode lottery. It is true that we give CCGs a lot of power in our system, in terms of making clinical decisions. The idea behind that is that they look at local considerations and balance the various options that they have. However, I will see to it that a review is done, hopefully within the next six months, of prescribing policies, and we will endeavour to come together with something that is more consistent, in a way that means we can actually make progress on this. I thank the hon. Gentleman for his contribution, and I thank everybody that has made an intervention in this debate. It has been a good debate, and a useful one for us to have had."

The transcription of the full debate can be found here <u>Commons debate on gluten-free prescriptions</u>

We continue to support the community dietitians when newly diagnosed coeliacs attend a group session, and I (Lyn) also recently attended a post-graduate training session for dietitians on coeliac disease, where I spoke about my experience of living with the condition. The students were all treated to a gluten-free lunch afterwards.

Your committee

Lyn Rasmussen (Group Organiser) Barry Clarke (Secretary) Tim O'Gorman (Treasurer) Graham Beniston Catherine Cox Helen Hayles Amanda Godfrey

Contact Lyn on 01572 723833 07729 759322

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Volunteering

We always welcome any offers of help of any kind. Just contact Lyn at any time, or one of the committee members at a meeting.

Children

Children are welcome at all our events. There is also a facebook page to support the parents of children with coeliac disease in Leicestershire – the link is https://www.facebook.com/groups/1551168565149539/

Here are the next dates for your diary:

Monday 28th November Annual Christmas Lunch at Leicester University, 1st
Floor Park Side, Charles Wilson Building, LE1 7RU. For information about the
venue see <u>Leicester university campus guide</u>

For the menu, see below. **All menu options are gluten-free**. Please can you let Tim have your choices by 24th November.



Stamps

Our biggest expenditure is on stamps for mailing out newsletters (over £300 a year). Please help us by either giving us stamps, or telling us an email address we can use. Also please let us know if you do not wish to receive any more newsletters. Emails are free!!!

Coffee mornings

1st Friday of the month at the café in Sainsbury's in Stamford 11am

1st Saturday of the month at Muffin Break, Highcross Centre, Leicester 10:30 -11:30 am



Contact Lyn if you would like more information

Further details and to book : Tim O'Gorman Tel : 0116 275 1273 Email : saraogorman2014@talktalk.net

• Wednesday 25th January 2017 *Burns Night Supper* at St Pius X Church Hall, 52 Leicester Road, Narborough LE19 2DF. The room and food will be supplied but help is needed on the night to serve the food. Please let Tim know if you would like to volunteer.

Further details and to book: Tim (as above)

Wednesday 15th March 2017 Evening meal at Leicester College.

Further details and to book: Tim (as above)

Saturday 13th May 2017 AGM at St Thomas More, 75 Knighton Road, Leicester LE2 3HN

Facebook group

We are implementing a facebook group which has been set up for any member of Coeliac UK who lives in Leicestershire or Rutland. Everyone in the group can use these pages to ask for advice, share information on supermarket foods, make restaurant recommendations (or restaurants to avoid), and to discuss any other matters relevant to living with coeliac disease.

The committee will also use these pages to inform the members of the group of planned events, and also of any other relevant news. The facebook group does not replace the existing Coeliac UK web site which can be used to find events and documents.

To join the group, or for further information, please follow this link:

<u>http://www.facebook.com/groups/coeliacukleicestershire</u>. You must have already signed up to facebook – see http://www.wikihow.com/Set-up-a-Facebook-Account if you need help to do this.

Our buffet

In October, we held a 'bring and share' buffet where members brought their own cooking and we had an entertaining tasting session. We all brought recipes for the items we had made, and these were sent to the attendees. Thank you very much to Catherine for organising this, and thank you to everyone who came on the afternoon.



Food offerings

Dipti Patel, a registered dietitian, has asked us to tell you about 'A Bite Different', which she runs. She provides take away meals which are suitable for coeliacs, and also runs cookery classes for different diets. The website is http://www.abitedifferent.co.uk/ and the address is 63 Roydene Crescent, Leicester LE4 0GQ, tel. 07799 385203. Dipti can also be contacted by email on abitedifferent@gmail.com

A fellow coeliac has recommended FarrinHeight Foods, based near Market Harborough. They cater for vegetarian, vegan and gluten-free diets and can be found at Market Harborough market on the 1st and 3rd Thursday of every month. They will also provide food to order for an event, or to take away and freeze. The website is http://farrinheightfoods.co.uk/; contact numbers are 07538 583341 or 01858 440585 (answerphone).

Regional Volunteer Conference

In September Catherine attended one of the regional volunteer conferences held by Coeliac UK in York. We covered a wide range of topics on the day including the following:

- An update on prescriptions and the restrictions being placed all around the country.
- The moves to update the national charity website and updating the look and ease of access to the venue guide and recipe database.
- How we can engage and retain members and develop the charity including rebranding and the promotion of the research and work the charity undertakes on behalf of its members.
- Developing local groups in ways the local members wish including a review of governance and local finance.
- Recruiting committee members and volunteers to help with local activities.

If you receive an email from head office asking for your opinion on their new logos etc please fill in the survey and give an honest opinion on their proposals!