

Leicestershire Group Newsletter April 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 sent us stamps – they are much appreciated and we are very grateful.

We had an excellent Christmas lunch at Leicester University – in fact, it was so good that we are planning to return this year. We also had an excellent evening meal at Leicester College in March – thank you to Tim for arranging these. Thank you also to Tasneem Dakri who attended the evening meal with samples of her gluten-free and vegan desserts (see <http://www.v-gd.co.uk> for more details).

Where possible we have supported the community dietitian sessions for newly diagnosed coeliacs. Catherine and I attended a post-graduate training session at Nottingham University for practising dietitians, which focused on living with coeliac disease. I also recently attended a training session for first year dietetic students to talk about my experiences with medical teams.

Thank you to Greg, who has kindly written his coeliac story which appears below. And thank you to Neville who sent us these recommendations for eating out gluten-free:

Rothley Fisheries, Cross Green, Rothley
Donelli's Restaurant and Takeaway, Market Street, Loughborough

Here are the next dates for your diary:

- **Saturday 14th May** *Annual General Meeting* of CUK Leics group – Saturday 14th May @ 2.30 PM at St Theresa RC Church rooms, 53 Front Street Birstall, Leicester LE4 4DQ
There will be a cookery demo courtesy of Glutafin, plenty of eats and the possibility of 'goody bags'. There is no charge for this event – but teas and coffees are to be paid for to defray the cost of venue hire; please come and drink lots! Car parking is in the church grounds.
If you are interested in being more involved with the group, please let any of the committee members know before the AGM, or talk to one of us at the meeting.
- **Saturday 4th June** *Visit to Saffron Acres Community project*, 432 Saffron Lane LEICESTER LE2 6SB @ 1.15 for 1.30 PM. £5 pp and children free. Car parking is available on adjacent streets.
There will be a talk on this innovative community project followed by a tour. Teas and coffees and soft drinks will be available but feel free to bring own sandwiches/picnic food. Please note this is a working environment/allotment site so appropriate footwear is indicated; children to be under close parental/carer supervision throughout.

Your committee

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

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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.

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

The project is an introduction to gardening, plant and fruit cultivation and the turning of the produce into jams and preserves. It is on a 12 acre site and has had great success; the jams and products were sold in Coop stores. The project has had National Lottery funding and education type visits like this are encouraged to publicise the project. Jams and produce should be available for sale on the day.

Bees are about to be introduced which it is hoped will lead to the production of honey; this will complement and enhance the already impressive output of the project. There will be an opportunity for supervised visits to the bees and hives. Further details and to book : Tim O'Gorman Tel : 0116 275 1273 E : saraogorman2014@talktalk.net

- **Sunday 3rd July** – why not join us for a g/f cream tea + scones at the Platform Café on the Great Central Railway, North Leicester (LE4 3BR). Times and costs will follow later.
- **2nd October** 3:00 – 5:00 pm – bring and share buffet items at Markfield. Details will be published on the web pages and in a future newsletter.
- **5-6th November** – Allergy and Free From show in Liverpool – if anyone is interested please let me know and we can think about hiring transport.

Lyn

Greg's Story - "A diagnosis by proxy"



Nearly three years ago, my identical twin brother was diagnosed with coeliac disease. He'd been suffering from horrible symptoms for years (stomach ulcers, countless stomach upsets and tiredness). Finally he was diagnosed correctly and then he began to feel well again.

He advised me to get tested, but I put it off. I was having no symptoms to speak of, was feeling fit and relatively healthy so didn't see the need. Anyway, about a year passed when my doctors encouraged me to attend a "Well-Man MOT Clinic" for the over 40s. I booked an appointment and took the opportunity to have bloods taken for coeliac testing at the same time. This was then done.

My results came back. I was given a good "bill of health" but the coeliac test came back as a likely positive indicator. I was then booked to have an endoscopy to confirm officially one way or the other.

My twin brother and my wife told me that I should insist on a sedative for the endoscopy. That sounded a good idea, obviously.

The endoscopy appointment came and I had already stated before-hand that I would like a sedative. I arrived at the Leicester General Hospital and was sat down in the waiting room. A nurse came up to me and chatted to me about

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



Contact Lyn if you would like more information

the procedure. She went on to say that I didn't need a sedative. Her words were "It doesn't make much difference, you get a local anaesthetic throat spray anyway and not having a sedative means you go home much sooner.". Well, I got talked out of having the sedative and this was, for me, a big mistake.

I was called in and the endoscopy began. It quickly became apparent that I was really struggling. I actually didn't know how to breathe as I was starting to panic. The whole thing was a nightmare. At no point did the staff explain that I could breathe through my nose! Sounds stupid, but I kept trying to gasp through my mouth and that was hopeless. I was held down as they continued and they took a couple of biopsies. This felt like burns inside my stomach, but I was more worried about breathing. It was over in a few minutes, but it felt like ages!

That experience was horrendous, so I would now **STRONGLY** encourage others to insist on a sedative and to keep in mind that breathing calmly through the nose will help enormously. Don't get diddled out of having a sedative like I did.

I got over that trauma and a few weeks later I was officially diagnosed with coeliac disease. This came as no surprise and I was okay about it.

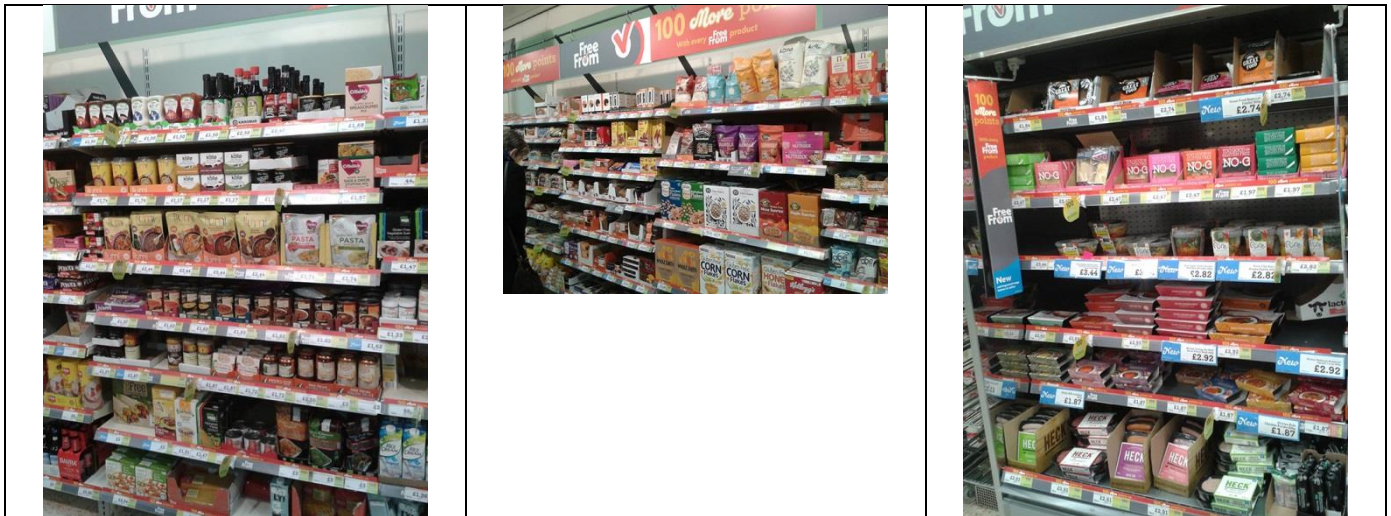
Because my twin was already a coeliac, he was expertly placed to offer great advice on diet and cautions etc. I had my own experienced personal GF coach! Not only this, but my wife had already done tons of research and was amazingly helpful, especially when it came to prescription foods and preparations of meals. I joined Coeliac UK and I find membership is a valuable thing indeed. Great publications; the "Directory" book and the "Crossed Grains" magazine, all superb and very useful.

18 months later, I've only been "glutened" a couple of times, which now makes me very ill indeed, so I've largely been fine. I was already a very keen cyclist so my fitness is excellent and I guess it's even better now that my body is properly fuelled!

Last year I did the "London to Brighton" cycle ride for Coeliac UK and I regularly meet up with the Leicester group for special meal events, coffee+muffin mornings once a month and even committee meetings! I certainly feel supported and part of a friendly community.

Supermarket news (an update from Catherine)

Morrison's are one of the latest supermarkets to sign up to the Coeliac UK gluten free guarantee. All 494 of its stores have agreed to stock at least eight basic items (white bread, pasta, cereal, flour, cereal bars, rolls, crackers and one other bread (brown or seeded). However, they seem to have gone much further than this with one of the best ranges seen.



The attached photos show the range in the Coalville store, from brands such as Illumi, Heck, Warburtons and Genius to name but a few, to a complete range of Morrison's own brands. The fridges contain quiche, pies, sausages, ready meals, children's meals and everything from puddings to beetroot falafel(!) with the shelf range extending from crumpets, pancakes, cereals, ready meals, sauces, to croissants and pain au chocolate, beer and basics like spaghetti and gluten free suet. Of course the sugar filled cakes are still on offer, but there is plenty of choice.

