



Group enquiries: coeliacsurrey@btinternet.com

June 2016

Welcome to the June edition of the Croydon Group of Coeliac UK Newsletter. A special welcome to any new members.

GP Gastroenterology Educational evening

Last week I attended the above educational evening for GPs in Croydon, where there were 4 presentations by the 4 Consultant Gastroenterologists. Dr Sanjay Gupta presented the audit that we had undertaken in 2014/15 where members of the group fed back their experience on "Annual Coeliac Review".

It was very sad to hear that none of the GP's in attendance (approx. 20 – 25) were actually following the Clinical pathway for annual review. The questions that followed were embarrassing, and showed that GPs have a serious lack of knowledge of Coeliac Disease and the importance of an annual review. But thanks to Dr Gupta and his enthusiasm I will continue working with him and the Dieticians on your behalf to bring equality across the GP practices in Croydon.

If you have any comments or suggestions I would love to hear from you. Jacqui.

Gluten Free Study – looking for Volunteers.

I am writing to you because we are starting a human intervention study in coeliac volunteers with a very low gluten content bread called "Gluten Friendly". It is very interesting because the flour is modified with a safe, simple and cheap technology. Therefore, it could have a great impact on the quality of life of this population. The study has been approved by the Ethic Committee of the University and evaluated by gastroenterologists and members of Coeliac UK.

It will be carried out at the Life Sciences Department of the University of Roehampton, London. However, for those living in the Berkshire area there would be a possibility to do it also in Reading. You can find an article about our study written by Alex Gazzola in his blog:

<http://foodallergyandintolerance.blogspot.co.uk/2016/03/gluten-friendly-study.html>

See below if you are interested. **Please respond direct** using the contact details in the flier below **and not** back to the Croydon Group.

Gluten Friendly Study

Coeliac volunteers needed!



Researchers at the University of Roehampton would like to investigate the potentially beneficial effects of GLUTEN FRIENDLY BREAD on gut health and inflammatory/immune response in coeliac disease patients

We are looking for:

- Men and women aged between 30-70 years old
- With medical diagnosis for coeliac disease (blood test and biopsy confirmed)
- On a gluten-free diet for a minimum of 12 months
- Not be extremely sensitive to exposure to gluten
- Able to attend 5 appointments over 1 month and donate faecal, blood and urine samples before and after bread intake.

You will be remunerated for your time.

If you are interested, please contact Triana Bergillos-Meca

[triana.bergillos-meca@roehampton.ac.uk](mailto: triana.bergillos-meca@roehampton.ac.uk);

Life Sciences Department

University of Roehampton

Whitelands College Room2007

London SW15 4JD



Gluten Free Prescriptions:

Following on from the request to get in touch if you were having issues with gluten free prescriptions and the fact that no one got back in touch I presume that no one is having problems!

How to save on Prescription costs -

If you need more than 12 prescribed medicines a year you could save money with a prescription prepayment certificate

You can buy a three- or a 12-month prescription prepayment certificate (PPC) - which works like a season ticket.

You could be losing as much as £190 by not buying a PPC. (Example based on three prescribed medicines each month with a 12-month PPC.)

For more information please use the link below.

<http://www.nhs.uk/NHSEngland/Healthcosts/Pages/PPC.aspx>



Eating out gluten-free

Getting hold of food or drink that is suitable to eat shouldn't be a massive challenge just because you've stepped out of your house. But we still hear regularly that eating out continues to be an issue for those on a gluten-free diet. We want this to change.

This year we (Coeliac UK) were contacted by a couple who told us that they'd driven over 250 miles for their first gluten-free fish and chips in 20 years, they were delighted! And while we were pleased for them, we don't want you to have to go the extra mile for fish and chips, let alone 250 of them.

Our next big campaign will be challenging restaurants, pubs, retailers and cafés across the UK to provide for those who need to exclude gluten from their diets. The campaign is now in the research and development phase, with a launch planned for 2017, and we want your views and experiences of eating out gluten-free to help us to design a campaign that is sharply focused on delivering the change that you want to see.

If you would like to be part of our campaign from the outset, please share your thoughts and experiences by giving 5 - 10 minutes of your time to complete our short questionnaire. There are different versions depending on your circumstances. Please click through and complete the one(s) most appropriate for you/your family:

- [Questionnaire 1 - I am on a gluten-free diet \(aged 16 years and over\) *](#)
- [Questionnaire 2 - I am a parent of a child on a gluten-free diet *](#)

*If the links for the questionnaires do not work please type the web address into your browser or copy and paste the links:

Questionnaire 1 - <https://www.smartsurvey.co.uk/s/Eating1>

Questionnaire 2 - <https://www.smartsurvey.co.uk/s/Eating2>

Izzy's Blog (aged 10)

I was hoping that during Awareness Week lots of the shops would have really good deals on the gluten free food. This would mean my Mum would be able to buy loads of my favourite things a lot cheaper. There were some deals but not as many as I would have liked. I didn't think the shops made much effort to show that it was Awareness Week.

With the lovely sunny weather, I have really enjoyed the Tesco free from Vanilla & Toffee ice cream cones and the Strawberry ones are nice as well.

Awareness Week – Izzy's mum

Like Izzy I felt that Awareness Week passed by without much impact. It is a shame that when you entered into some of the major supermarkets they didn't have a banner showing it was Coeliac Awareness Week. Aldi (in Coulsdon) brought in a range of gluten free products: - Nestle Cornflakes, Mrs Crimbles macarons, Genius breads and crumpets, a selection of biscuits, cake mixes, crisps and sauces. Aldi's prices were very good and if they could manage to have a small range of gluten free basics I might shop there more often.

Disaster!

As a carer for a child who has Coeliac Disease, I am extremely careful about cross contamination, checking labels and making sure Isobel doesn't eat anything containing gluten.

Unfortunately, that was not the case a week ago. I accidentally swapped Isobel's pack lunch (gluten free crackers) with her brother's (which did contain gluten). Isobel ate the gluten containing crackers and really enjoyed them! It was not until she came home and I emptied the lunch boxes did I realise my terrible mistake. I asked Isobel how she felt (even though it was 5 hours later) and she said she felt OK. I explained to her what had happened and that she may start to feel unwell. I didn't sleep well at all that night partly due to worrying if Isobel would be ill and because I felt so guilty. I am pleased to say that Isobel's first taste/experience of gluten in three and half years was all OK with no illness. How lucky are we!

Editor's note: We all make the occasional slip up, or "glutened" when eating out, but eating gluten or "cheating" on purpose because we don't react is NOT a good idea. It is said by the medical profession that if we eat gluten even by mistake you do 3 months worth of damage to the villi which means we do not absorb nutrients as well and it takes time for the villi to repair.

So PLEASE don't think it is ok to have the occasional item containing gluten.

Social Media News

Pizza Express – dough balls

People seem to be really enjoying the new gluten free dough balls!

Selfridges

The food hall has a good range of gluten free products, cakes and bread. They are now stocking Artisan Gluten Free Bakery (formerly Romeo's) bread. Don't forget there are many other goodies there, such as Elvira's Secret Pantry (fridge section) and Borough 22 donuts!

Holland & Barrett

If your local H&B does not have the stock you need, you can order online for click and collect. New(ish) store in Croydon.

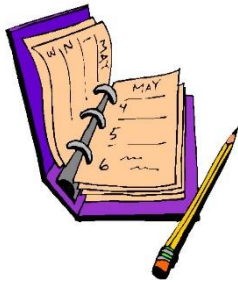
Wyevale Garden Centres

Are now doing gluten free fish and chips. Have you tried this? and is it available at the Purley Way Branch?

Find us on

<http://www.facebook.com/> Croydon Group of Coeliacs.

We are a “closed” group but anyone from the Croydon Group can join, it just means the “world “ cannot see us discussing symptoms etc. Why not click and join us – lots of useful information!



Dates for your diary

- **Saturday 2nd July 2016 Coeliac UK Annual AGM & Conference**
Bath RaceCourse Lansdown Bath BA1 9BU
Lots of Gluten Free exhibitors available (check out your latest copy of Crossed Grain for more details.)
- **Wednesday 7th September 2016**
Dr Sanjay Gupta Consultant Gastroenterologist at Croydon University Hospital.
Venue: Shirley Oaks Hospital
More details to follow.
- **Allergy & Free From Show – 8-10th July London**
www.allergyshow.co.uk/go/CG-Summer for free tickets

Future of the Group.....

I have now been organising the Croydon Group for the past 5 years, and recent attendance at meetings is falling, and lack of interaction by members following monthly newsletters is causing us to review whether you wish the Group to continue or not.....

We understand that there is a lot of information provided to you by Coeliac UK, via the internet and just in general for established Coeliac patient's/members life is so much easier than it ever used to be.....

So do we continue to work on your behalf (often unseen and in the back ground.....)
PLEASE let us know your feelings. It would be a shame that if Croydon CCG decide to
remove Gluten Free prescriptions and we are no longer in existence then GF prescriptions
will go without a fight! We are stronger as a group and as a voice in Croydon. Thursday's
GP Meeting proved to me just how much education we need to give them in order to
improve our care across Croydon.

Any comments suggestions for future meetings please do let us
know.... Coeliacsurrey@btinternet.com

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