Sevenoaks Area Coeliac Group

TALKABOUT

For all your gluten-free gossip, news and events

February 2012 Edition 26



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Note from the Editor

Dear Reader

Happy New Year from all of us at the Sevenoaks Group! We hope you all had a great Christmas.

We are pleased to report that our monthly coffee mornings are back on at the newly refurbished Otford Sainsbury's. Our onsite reporter Daphne has reported that it is very spacious and has a variety of gluten-free treats at the counter and the staff appear to be more knowledgeable on what is gluten free on the menu. We hope to see some of you at the next coffee morning. Check out the Forthcoming Events section to find out when the next one is.

The next big event will be the AGM in March which will be followed by the children's party. We would love to see lots of you there this year. Please contact Gill to let her know you are coming along with the children.

We have also done an article on the prescription cuts. We would love to hear your views and we will be discussing this further at the AGM.

As usual, we have some great places to eat that our members have recommended. Let me remind you that we don't check these places ourselves so please do ring ahead and check that they can cater for you to avoid disappointment.

In this edition we have featured some great ideas for Afternoon Tea. Mother's Day is approaching so why not treat your Mum at home this year and put together a gluten free feast. Or organise an Afternoon Tea event for the Silver Jubilee celebrations.

We hope you enjoy this edition and as always we welcome your feedback and suggestions for future editions of Talkabout.

Best wishes Gill – The Editor

Places to Eat and Useful Information

Have you got a local restaurant that looks after you when you eat there and understands your needs? They don't need to advertise as gluten-free on the menu but are they prepared to put themselves out a little to look after you? If each and every member contacted us and let us know about their favourite restaurant, then imagine the wonderful selection of restaurants we could all try!

If you have some useful information to share with other members then please get in contact - you'll find my contact details on the back page of the newsletter. We look forward to hearing from you soon.

Facebook Forum for Teenagers

Following on from my Walkers campaign and some of the comments on the Facebook group, it has become clear that there is no forum available for our Coeliac / gluten-free children to meet and talk. Therefore, I have set up a new Facebook group called 'Gluten Free Kids' -

<u>https://www.facebook.com/groups/glutenfreekids/</u>. It is, as far as I can find, the only discussion group for kids with Coeliac Disease or who follow a gluten-free diet where they can chat, make friends, let off steam, and be with other kids who actually understand what they're going through on the UK scene. This is a strictly 'No Adults' zone (except the moderators to keep an eye on things) so please point all the kids and teenagers you know to this new group. It has been set up on Facebook as this seems to be a social media that the kids like and understand. Parents, please take a look at the 'Mission Statement' to understand the level of moderation and supervision that will be undertaken on the group.

Debra Samuel

Please be Aware - This was brought to my attention by a member St John's Fish Bar St John's Road, Tunbridge Wells Tel: 01892 521040

In our last edition we gave details about the above fish bar in Tunbridge Wells selling gluten-free fish in batter. One of our members popped in one Friday night and noticed that they were cooking the gluten free fish and chips in the same fryer (and oil) as the rest of the non gluten-free fish. There is a possible contamination issue. Please contact the fish bar and check before purchasing.

The King's Arms Hotel & Restaurant Woodstock, OX20 1SU. Tel: 01993 813636.

If anyone is looking for a meal in this area (Blenheim is adjacent), I can certainly recommend the restaurant. Friends had booked for us to have dinner with them here on the strength of several recommendations they had received. When booking they were impressed by the hotel's reaction to the question about coping with a gluten-free diet. This impression was further enhanced on seeing a separate gluten-free menu already on our table when we arrived. There was a wide range and choice for both starters and main course, and, although quite pricey, the quality was good.

Tony Gifford

Longfield Fish Bar 22 Station Road, Longfield, DA3 7QD Tel: 01474 704083

I just wanted to let everyone know about the Longfield Fish Bar. This is a very popular take away situated on Station Road, the main street in Longfield, not far from Waitrose (for easy parking).

Dave and Paul, who run the fish bar, are both really friendly, helpful chaps and despite being a bit nervous at first, they're now offering 'Gluten Free' on a regular basis, every Tuesday evening. At the moment, they're asking if people would ring in advance to let them know they require 'gluten free', as this enables them to get the oil heated in the separate fryer, and get your choice of fish ready (usually cod, haddock or rock, and sometimes other options like skate are also available).

I hadn't eaten proper fish and chips for 10 years, apart from a few occasions at Rick Steins in Padstow, so to have this on my doorstep is absolute heaven. They make every effort to ensure their staff understand about keeping the gluten free items separate and have really gone out of their way to start offering a service which they were initially a little wary of. And if that isn't praise enough, the portions are generous, reasonably priced and cooked to perfection - absolutely marvellous!

Elaine Granger

Gluten Free Sandwiches

Starbucks Coffee shop has a couple of gluten free sandwiches to offer as part of their range. Marks and Spencer also have a choice of 2 gluten free sandwiches on their pre-packed shelves to take away (egg mayonnaise and ham salad). This is great news!

The Hare Public House Langton Green Langton Road, Tunbridge Wells TN3 0JA Tel; 01892 862419

The food here is excellent and they have a special gluten free menu that is very extensive and is quite a treat. Well recommended.

Joy Milne

Abigail's Kitchen

Turnmill Street, London EC1M 5QU

They are very understanding with gluten, wheat, nuts and dairy free food. They serve hot food and salads. Reasonably priced too.

Sheila Drury

When In Rome..!

One of our members found a great restaurant when they were in Rome which catered for her gluten free diet fantastically. They understood what was required immediately which is a rare treat. It was called L. Europeo and was on Via Principe Amedeo and the telephone number is 06. 4818500.

Valentina

Sevenoaks High Street

Valentina is an authentic Italian delicatessen, restaurant and shop. In the restaurant it serves gluten free pasta and is well worth a visit according to some of our members.

Strada in Tunbridge Wells

I took my daughter to eat at Strada with some friends for a birthday treat and I rang ahead to check what they served as part of the children's menu. There wasn't much available that was gluten free but they were happy for me to take some gluten free pasta which their chef cooked and he also prepared some fresh Bolognese sauce for her. I was very impressed with their flexibility.

Smith & Western Restaurant Lingfield and Tunbridge Wells

They have a free from menu list so you can check what food is available for you to have. The burgers are gluten free and it is a great place to eat out with the children. They love the atmosphere and the food is good! Check the website for locations <u>www.smith-western.co.uk</u>.

Forthcoming Events

Recently we have found numbers diminishing at events and we have decided to concentrate on events that we feel are very valuable to our members. We have recognised that our newly diagnosed members benefit greatly from the monthly coffee mornings and our regulars also enjoy coming along for a coffee and a chat.

Therefore, for the next few months we will be concentrating on Coffee Mornings every month at Sainsbury's (see below) and will run events in the future if we feel there is a demand for them. All suggestions are welcome.

Coffee Morning - Third Saturday of every month

(18 February in Tunbridge Wells, 17 March in Sevenoaks, 21 April in Tunbridge Wells, 19 May in Sevenoaks)

If you are newly diagnosed and want to find out more this is a very relaxed way to meet with other coeliacs to share ideas and have a chat. We welcome all members. We meet between 10.00am - 11.30am. We look forward to seeing you soon - look out for the Crossed Grain magazine on the table. We meet at alternate locations each month. One month at Sainsbury's Café in Sevenoaks (Otford Road, TN14 5EG) and the next month in Sainsbury's Café in Tunbridge Wells (on Linden Park Road, TN2 5QL, just off the A26 Eridge Road).

Saturday 24 March 2012

AGM ~ 10.30

Children's Party ~ 11.15 - 12 45

Otford Methodist Church Hall, High Street, Otford TN14 5PH

Please note the new venue. Visit the online webpage for the location of the church www.otfordmethodistchurch.org.uk/contactlocation.html.

At the **AGM** we will be talking you through the highlights of the past year and giving you a general overview of our financial situation. Perhaps you would like to get involved with the Sevenoaks Group? – You can volunteer as little or much time as you wish! After the AGM during the children's party there will be an opportunity to share coffee and conversation with fellow coeliacs in the coffee lounge.

Following the AGM we will be having a **party lunch for the children** (age up to 10) with lots of fun and games and of course gluten free goodies. Please let Gill Howe know if you will be coming along to the party. Email and telephone number on the back cover of this newsletter.

Coeliac Disease and Me

Personal Account – David Apps

I am now approaching the young old age of 69. Looking back to when I was younger, I did suffer from stomach aches, sickness and tiredness. This was always put down to being worried or excited to what was going on at the time e.g. a major cricket or football match, a new girlfriend, or probably the arrangements going on for Marden Carnival Week - a major part of my time during my late teens and early 20's! The symptoms never remained long and I was soon back to normal.

In about 2000/2001 I began to have 'men's' problems with the urinary tract. I visited a BUPA specialist who diagnosed an enlarged prostate. At that time he was quite happy to just watch and wait and all was well until early 2007 when the problem flared up again. This time he arranged for me to have a prostatic biopsy, which was done in June that year.

This is where my coeliac condition was very unusual compared to most other coeliac's, including my older brother, who had terrible stomach/bowel pains, loss of weight and tiredness problems for at least 20 years, without being diagnosed a coeliac!

On the Monday prior to the biopsy on the Wednesday, my coeliac symptoms dramatically arrived without any warning. I had violent diarrhoea, stomach ache and cramps etc. These symptoms were to continue for a very long time and I also lost a lot of weight. On the Wednesday I went ahead with the biopsy. How I got through it, I don't know - it was one of the most painful experiences of my life.

However, there were no nasty cancer cells, so that was good. I had put the symptoms down to stress and being worried about what they might find. When the symptoms never went away I quickly went back to the Doctor.

Working as I did for a major Pharmaceutical Company, we were blessed with private medical insurance. My doctor then arranged for me to see Dr Dunk at the BMI Hospital in Eastbourne. After discussing my symptoms and explaining that my brother was a coeliac, he thought this was my problem too. The next week he arranged an endoscopy to confirm his diagnosis and I was announced a Coeliac. I was put onto a gluten free diet immediately and was told that I would start to feel much better within the next few weeks, although I may not be fully back to normal for about a year.

However, although keeping to the strict gluten free diet, given by the Dietician, nothing changed. All of the symptoms were still there and getting worse instead of better and on top of that I was still losing weight! I went from a naughty 11 stone down to 8½ stone. My wife ensured that I kept strictly to the diet. This is easy for me as I prefer plain old English food.

I was due to retire from work at the end of 2007. In my position as Sales Operations Manager, I looked after the total sales force and negotiated with our major wholesalers, therefore I had agreed to stay for a 6 month period to train my successor, so thankfully I still had my medical insurance.

Dr Dunk was worried about my condition and arranged for me to see Professor Ciclitira at the London Bridge Hospital. He is one of the top Gastro Specialists in the country and specialises in coeliac disease. After an initial duo-endoscopy and colonoscopy he remarked that my intestines were still as smooth as a baby's bottom. I then had various tests and was given very large doses of steroids. Gradually the symptoms began to ease and life got back to normal. I have had a further two setbacks where I have had to have large doses of steroids, but now my condition is quite good.

I know that if I eat anything wrong or get any contamination by mistake then I will get my symptoms back within a few hours. I am still under Prof Ciclitira, who is now at St.Thomas Hospital in London, as one of his guinea pigs as I cannot afford Private Insurance any more.

Prior to Coeliac Awareness Week I arranged with our local Morrisons Supermarket in Crowborough to have a display stand in their shop frontage. The main reason for having this display was to create awareness of the coeliac condition and its symptoms. We spoke to at least 10 people who had possible symptoms and we advised them to talk to their own doctor about coeliac disease.

I hope that this account of diagnosis is of interest and shows how coeliac disease affects us all differently.

As a mother to four children, three of whom cannot have gluten, and unable to eat gluten herself, Annie knows that there are very few options for Coeliacs in the UK who wish to dine out.

Many restaurants now offer a gluten free option but sadly this is not always accompanied by a true understanding of the dangers of cross contamination. All too often a coeliac will eat something they are told is "safe" only to suffer symptoms afterwards. Having a waiter remove bread from your plate at the table and saying "it's alright now, you can eat it" is something that should be fiction – but is not. Annie is not alone in having been glutened on a number of occasions by a meal that was meant to be gluten free.

Annie set up her Supperclub in order be able to offer a safe, relaxing dining experience to coeliacs and others on a gluten free diet.

How it Works

Annie and her Maître d' invite you to join them for a five-course, gluten free dinner at a secret location in Bromley. Full directions to the secret venue will be sent out upon receipt of your booking. All of their food is gluten free, cooked in a gluten free kitchen. If you are vegetarian or vegan, please let them know at the time of booking. At the end of the evening you will be invited to make a donation for your meal, £25 being the minimum amount customarily given by each guest.

The Evening

Annie and her Maître d' enjoy welcoming new friends to spend an evening with them. You can expect to be greeted with a light Apéritif to stimulate your appetite for the meal ahead. Next is L'entrée, which is often mistakenly used to refer to the main course of a meal but it is in fact the start of the dinner that is presented to guests. Let Plat Principal - the main course typically includes either meat or fish, served with side dishes of salads, rice, or pasta. Vegetarians are happily catered for if requested at the time of booking. Le Dessert may be either hot or cold. Since it is served towards the end of the dinner, dessert is commonly light and small – however if Maître d' prevails you can be sure that it will be rich and probably include chocolate! Finally, Le Café is offered to finish off the meal.

If you would like to find out more or make a booking please contact Annie via her website at <u>www.anniesupperclub.co.uk</u>.

Prescription Guidelines

Many of you may have been affected by restrictions on your prescriptions. I received this email from one of our members:

"I've just received a letter from my GP, who has been a great support for many years, apologising for the change to West Kent PCT's policy regarding gluten free foods. The only change for me is that I will no longer be able to have FRESH bread, which I preferred and kept in the freezer. This seems a shame because personally I find the various long life loaves tasteless."

Maggie Fanshawe

This is the letter that she received:

"We are writing to notify you of a change to West Kent PCT policy regarding the supply of Gluten Free foods on prescription. In future we will only be providing long life bread, flour, flour mixes, pasta and crackers on prescription. The decision has been made as there are now a wide range of gluten free foods available from supermarkets. We are aware that gluten free products cost more than the equivalent gluten containing items, however we consider it reasonable to expect patients to spend a similar amount on these foods as those who are able to eat gluten-containing products. West Kent PCT has therefore decided that a fairer system would be to provide some, but not all gluten free foods on prescription as a contribution towards the cost of maintaining a gluten free diet. You many choose to purchase additional items."

We haven't heard from many of our members about this issue but it must be affecting some of you. Coeliac UK has been petitioning on our behalf and has also put together some new guidelines. These are available from Coeliac UK and via the website. If you haven't seen the guidelines yet, they could be quite helpful if you are in discussions with your GP as it explains how many units you are entitled to per month. It explains that you should be able to choose how you make up that 14 (for most of us) units. For example, they should not be deciding for you that you cannot have fresh bread, they should be showing you what is available and you choose what you would like. A 400g loaf of bread is 1 unit. It lists all food items and how many units they are worth.

As Maggie explains "It seems such a shame to give up the fresh bread after waiting over 40 years for it. There's no way I can afford £2 or more on a 400g loaf." We will be discussing this issue further at the AGM and would like to hear your views.





Saturday 24th March 11.15 - 12.45

Otford Methodist Church Hall High Street Otford TN14 5PH



To book your place for fun event, please contact Gill Howe on: 07971 481150 or email: gillieh@tiscali.co.uk

Marks & Spencer Gluten Free Online

Marks and Spencer have recently launched a new gluten-free ordering service. You can now choose from a selection of your favourite M&S Made Without Wheat and other gluten-free products to order online and simply collect from your nearest M&S store (excluding Petrol stations and some smaller Simply Foods stores).

To find out more please visit <u>www.marksandspencer.com/dining</u>.

Allergy & Free From Show 2012

Coeliac UK has again teamed up with the newly rebranded Allergy & Free From Show to offer unlimited FREE tickets to all Members (worth £10 each).

The show, which will be taking place on 18 - 20 May 2012 at Olympia's brand new West Hall, London, will be packed with even more Free From features. Sample the latest gluten-free foods, enjoy cookery demonstrations, chat with Coeliac UK staff and get advice from Coeliac UK dietitians.

This year we are also delighted to be running a new workshop on the Saturday afternoon entitled; 'Campaigning for people with coeliac disease: Awareness Week, the Gluten-free Challenge'.

Get the dates in your diary and access unlimited free tickets for you, your friends, family and colleagues via their website at <u>www.allergyshow.co.uk</u>.

Social Media

Don't forget that the gluten-free debate continues online, where we encourage conversation about the things that matter most to you and post useful information of our own.

If you want to join in then find us on Facebook or follow us on Twitter. Alternatively, if you want to see our selection of videos concentrating on coeliac disease and the gluten-free diet visit our YouTube channel.

Afternoon Tea Treats

Sandwich Ideas

You can buy gluten-free fresh bread in most supermarkets now, so you should be able to easily make a nice selection of sandwiches. Why not try some of these traditional fillings;

- Salmon and cucumber
- Roast beef and horseradish
- Egg and cress
- Smoked salmon and cream cheese
- Cheese and salad
- Cooked gammon and mustard

You can't have afternoon tea without cake. Why not make a classic Victoria sandwich using the recipe below and fill with fresh cream and strawberry or raspberry jam and top with fresh strawberries. Or use the mixture to make small fairy cakes and decorate with coloured icing.

Victoria sandwich cake

Ingredients

- 100g (4oz) butter or margarine
- 100g (4oz) caster sugar
- 2 eggs
- 1 tsp vanilla essence
- 150g (6oz) gluten-free flour
- 1 level tsp baking powder
- Icing sugar to dust
- Jam and whipped cream to fill

Method

- 1. Cream fat and sugar until light and fluffy.
- 2. Add eggs one at a time and beat thoroughly. Add vanilla essence. Add sifted flour and baking powder.
- 3. Divide between two tins and bake in the centre of a preheated oven (180°C, 350°F, Gas Mark 4) and bake for 20-25 minutes.
- 4. Allow to cool on a wire rack and fill with jam and cream. Dust the top of the cake with icing sugar to serve.

Scones and Cream

What better way to eat strawberries than with fresh cream and a nice scone! Use this recipe to make fresh gluten-free scones or buy some from the Free From section of your local supermarket.

Gluten-free scones (makes 8)

Ingredients

- 100g (4oz) gluten-free flour*
- 1 rounded teaspoon baking powder*
- 25g (1oz) sugar
- 50g (2oz) margarine
- 1 egg, beaten

Method

- 1. Sift flour, sugar and baking powder into a bowl. Rub in the margarine. Mix in the egg to make a soft dough.
- 2. Roll on a floured surface, cut into rounds and place on a greased baking tray.
- 3. Bake in a preheated oven at 200°C, 400°F, Gas Mark 6, for 10-15 minutes.
- 4. Leave to cool, slice in half and serve with fresh strawberries and clotted cream.

Drinks

If you are wondering which drinks to enjoy, there are plenty of both alcoholic and soft drinks which are gluten-free.

- Champagne and Pimm's are gluten-free.
- Cider, wine, sherry, spirits, port and liqueurs are gluten-free.
- Beer, lagers, stouts and ales contain varying amounts of gluten and are therefore not safe for people with coeliac disease. You can buy specially made gluten-free beers and lagers and these are usually found in the Free From section of the supermarket and some health food stores.
- Fruit juice, flavoured waters, cordials and fizzy drinks are gluten-free. Barley squashes are not suitable.
- If you are going for a traditional tea party, all teas are gluten-free so why not try some different teas like Lady Grey or Darjeeling.



Talkabout

Sevenoaks Area Coeliac Group

Please send your letters or enquiries to:

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