

Sevenoaks Area Coeliac Group

TALKABOUT

For all your gluten-free gossip, news and events

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Sevenoaks Coeliac Group
 **Voluntary**
support groups

Branch Committee

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Note from the Editor

Dear Reader

Happy New Year from us all at the Sevenoaks Coeliac Group. We hope you all had a great Christmas and have enjoyed some time in the snow.

Our Committee Members were busy at the back end of last year keeping up-to-date with what is going on at Coeliac UK and elsewhere when a few of them attended the Volunteers Conference. They had a very interesting day and David has written a piece on pages 12-13 so you can see what was discussed on the day.

We have a very good relationship with Darent Valley Hospital and over the years some of our committee members have been very involved in discussions with the hospital to improve gluten free food options for inpatients. Fiona, Rita and Daphne had a great meeting in November to see how they are getting on and to discuss some better ways to deal with some of the problems they find. You can read more on pages 8-9.

We have our AGM coming up in March and this year we would like to invite you along to an Afternoon Tea which we will be preparing for our members. Check out the timings for the AGM in the Forthcoming Events section. We hope to see lots of you there.

Please don't forget to tell us about your favourite places to eat where they cater for your dietary needs. It's great to share these with fellow members.

Happy Reading!

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.

Juvela – did you know?

One of our members has discovered that you can get breakfast cereals on prescription. The following Juvela products are available and you will need the PIP Codes when talking to your doctor or pharmacist. Juvela Flakes 300g (PIP Code 371-1652), Fibre Flakes 300g (PIP Code 371-1660) and Pure Oats 500g (PIP Code 371-1678). The oats don't need to be cooked so can be used to make up muesli.

Gluten-Free Pizza Alert!!!

We went to Domino's Pizza on Tuesday in Biggin Hill and my son Dominic had the gluten free pizza with chicken, sweetcorn and mushrooms - it cost £9.99 and he said it was great! We have also been to Pizza Hut at Purley Way in Croydon and he said that the gluten free pizza was really good there as well.

Lorraine Laurence

Tea Rooms

Just to let you know that there is an excellent tea room at Duddleswell that serves wonderful gluten free scones, meringues and roulade. It was a lovely surprise after walking in the Ashdown Forest to have a cream tea which was delicious. Needless to say we have been back! They have a website at www.duddleswelltearooms.co.uk

Jean Brown

Annie's Larder

The Courtyard Cafe in Westerham now stocks our gluten free cakes. We are supplying them with lemon cake, carrot cake and chocolate cupcakes. Our cakes are certified gluten free (under 5ppm) and are supplied to the Courtyard sealed. We have also made them aware of the issue of keeping them covered, separate and using different knives etc.

The feedback is that they are selling well but I thought it didn't hurt to flag them up to local coeliacs!

We are also looking at ways to be able to supply them with our fresh gluten free baguettes (currently receiving rave reviews on our London gluten free lunch delivery service).

To find out more about Annie's Larder visit her website at www.annieslarder.co.uk . *Annie*

The Spaghetti House, Argyll Street

When we were in London recently and looking for a pre-theatre meal we were surprised and delighted to find that The Spaghetti House in Argyll Street, which is really close to the Palladium, has started serving gluten free pasta. Even better news is that it's a London chain – they have 12 restaurants which all seem to be beside tube stations. You can check it out at www.spaghetthouse.co.uk *Daphne Paterson*

Bella Italia

The Bella Italia chain, which can be found in and around London also do gluten free pizzas which are pretty good! You can find out where their restaurants are at www.bellaitalia.co.uk. *Elaine Bowdery*

Deep Blue Fish and Chips

Unfortunately, the Chislehurst shop, which used to sell gluten-free fish and chips, was sold last summer. Please refer to their website www.deepbluerestaurants.com for all store and restaurant locations. Please check beforehand to see if they cater for gluten-free diets.

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

(March coffee will not run as AGM instead, 20th April in Sevenoaks, 18th May in Tunbridge Wells, 15th June in Sevenoaks, and 20th July in Tunbridge Wells)

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 and 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 (Oxford 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).

AGM and Afternoon Tea

Saturday 16 March 2013 – 2 - 4pm

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

We will be talking you through the year's events and updating you on relevant issues. Following the official part of the day we will be offering a tasty Afternoon Tea for our members so please come and along and join us for a scone and cup of tea.

If you have any nice unwanted Christmas or other presents that you would be happy to donate we will be holding a small table top auction on the day.

Sky Dive in Aid of Local Coeliac Group

You may recall that last year the Lady Captain of Broke Hill Golf Club, Anne Payne, approached the Sevenoaks Coeliac Group and said that she would like the Group to be her chosen charity for the year which means that any funds that she raises throughout the year will come to the Sevenoaks Coeliac Group which is fantastic.

Two members of the golf club decided to do a charity skydive and wanted all monies raised to go to the 2 Captain's Charities. Here is Helen's story.

"Christopher Mountain and I, Helen Preston did a joint Tandem Skydive on Bank Holiday Monday 27th of August, at Headcorn Airfield. We successfully jumped from 12,000ft, with a freefall of 30-40 seconds at 120mph.

The jump took place at around 3pm as the weather had been touch and go throughout the morning, but we were lucky that some of the clouds disappeared and the sun came out. I know that Chris would strongly agree when I say that taking part in a skydive is one of the most exhilarating and exciting things you can do. We felt on top of the world for the next few days as the adrenaline takes quite a while to wear off!

Chris and I have known each other for over a year now through working at Broke Hill Golf Club. We decided to jump on behalf of our Captain's Charities of Anne Payne and Peter Riley.

Peter is supporting Children with Cancer and Anne is raising funds for Coeliac UK. Both charities are very important to them so being able to have raised a nice amount of money was very satisfying. Our total raised amounted to £499.60 which will be split 50/50 between the charities.

We are immensely grateful to all of our families, friends, work colleagues and members at Broke Hill Golf Club for supporting us in our fundraising."

Helen Preston

Meeting at Darent Valley Hospital 20th November 2012

Going into hospital is always a stressful time and you don't need to be worrying about whether the food is going to make you poorly. We followed up on some of our member's experiences of being offered unsafe food whilst spending time in Darent Valley Hospital (DVH). Fiona, Daphne and Rita met with Eileen Brookson, Head of Nutrition and Dietetics, Clare Jansen, Dietician and Alan Hinds, Catering Manager to discuss some of the issues that can have a detrimental effect on coeliac patients in their care.

Some years ago the then head of dietetics, Judith Webb, took on board our concerns and observations and as a result made a lot of changes to make eating in DVH much safer, even to changing their food supplier to one who had a larger range of GF meals and products on offer.

Both Fiona and Daphne have experienced being offered unsafe food in hospital and whilst they were able to point out the error, our concern is that another person may just accept that what they are given is gluten free and may have their health compromised further by lack of understanding.

In Daphne's case, on one occasion after ordering a rice pudding dessert she was served with semolina and Fiona had sage & onion stuffing served with a roast. With both having had similar experiences we thought we ought to find out what was going wrong.

There are gluten free meals readily available and these are published on their Core Gluten Free schedules on a fortnightly basis. Gluten free bread is available and a toaster marked gluten free will be sent up to the ward on request. We had a slight problem with this because there is nothing to stop anyone cross contaminating it so we suggested they may like to consider providing 'Toastie Bags' or perhaps take your own. Alan, the Catering Manager also makes gluten free breakfast cereal available and has added Mrs Crimbles and Free From products to the snacks menu. Patients are also welcome to keep their own GF bedside snacks. Alan said more changes are on the way which will include specific gluten free menus which would make the process much clearer for elderly and sick patients.

Although GF food is available in DVH it seems that the one weak link is with the Service Team Assistants (STA's) as they serve the food. The nurse in charge is supposed to ensure it is correct and hand it to the patient but STA's do hand out food in busy times. If there is a new admission and the STA is unaware then it is quite easy to give someone the wrong food. They do try keeping STA's to the same wards, apart from holidays and days off, so they get to know their patients, which helps.

Eileen asked if we would like a sign over the bed to alert staff to a patient needing GF food. We were slightly surprised because, we have asked for this in the past and been told it contravened the data protection act so could not be done. We replied with a unanimous YES as we think this could be very useful. Patients can always opt out if they feel their privacy is at risk.

Another weak area is being admitted in an emergency when there is no time to alert staff to dietary needs, although probably, in an emergency food will be the last thing on one's mind. However, patient notes are computerised and can be accessed by hospital personnel so it was suggested that you get your GP to make a note in the 'Allergy' box on the patient notes saying COELIAC or GLUTEN. We know it's not an allergy but it is a way of alerting the hospital staff.

If you know you are going into hospital it would be wise to contact the Dietetics Department in advance to get them prepared and the nurse in charge will talk to you about meals when you are admitted to the ward.

Having talked through the issues that we had raised, the team asked if our members would provide feedback to them on their hospital experiences. If it is a comment about another hospital please make that clear but do not name the hospital. This is a data gathering exercise to try to make improvements at DVH and would be really useful. Your comments can be emailed to Fiona Turnbull at fi.turnbull@talktalk.net.

Finally and on a lighter note, Eileen asked if any of our members knew how to make gluten free chapattis as they have not had any success and had lots of requests for them. I wouldn't mind knowing also.

We are very grateful to the team at DVH for making the time to talk to us and listen to our concerns and we really appreciate having what we think of as a very special relationship. They are willing to listen so let us give them some help which in turn will benefit us.

COFFEE MORNING

Come and join us

WHERE?

Sainbury's Café

Tunbridge Wells or Sevenoaks /Otford

Look under 'Forthcoming Events'



WHEN?

On the third Saturday of most months between 10.00 and 11.30

WHY?

For a cup of tea or coffee and a chat with fellow coeliacs



Tomato & Bacon Soup

INGREDIENTS

- 2 oz hard margarine
- 2 medium size onions - chopped
- 3 x 400g tins of tomatoes
- 7oz (or more) cheap cooking bacon/ham (smoked is best) - chopped
- ½ tube tomato puree
- 2 large potatoes - peeled & cut
- 3 pints veg stock (4 veg cubes)
- 1 heaped tbsp sugar
- Salt & pepper
- ½ a chilli and some garlic cloves to taste.

METHOD

1. Boil the potatoes until cooked - retain the water, see 3.
2. In a large saucepan melt the margarine & soften the onions & bacon.
3. Add the potato water and liquidise or hand blend until pureed - return to saucepan.
4. Add potatoes and all other ingredients and simmer for about 30 mins.
5. Liquidise (hand blender for this) and reheat.
6. Serve in warm bowls with crusty bread.

Volunteers Conference Birmingham 2012

I was looking forward to my first Coeliac Volunteers Conference. It didn't let me down, it was very well organised, friendly and informative. My one surprise was that only 33 Local Groups attended out of a total of 94. The numbers were the best ever, but this was because some groups had 6 attendees.

The Conference was made up of presentations from the 3 sponsors plus some from Coeliac UK. The opening speech was made by Gillian White, Vice Chair of the Board of Governors. She highlighted the work being done by Coeliac UK, the various research projects in operation and the work being done with local PCT's and Clinical Commission Groups, regarding prescription products and costs.

Discussions were also being held covering, early and missed diagnosis of coeliac disease, particularly in children. She used the Olympic Games as a way of showing how volunteers make a tremendous difference to charities, highlighting our Awareness Week as a special point. Without all the volunteers it would not be as successful. However, we need to capitalise on this benefit, to maximise the charity as there is still so much to do.

Dr. Ruth Howard – Consultant Clinical Psychologist - University of Birmingham discussed her research grant from Coeliac UK which was based on how young children with coeliac disease understand their condition and the problems faced during their development. A DVD was produced showing how a group of children coped during diagnosis – their understanding of the disease, the diet, working with their diet in school/play/eating out with friends and how they manage the disease. It was very interesting and well worth watching for any young child recently diagnosed, or with talks in schools.

Annette Woolman - Coeliac UK presented details of the current situation regarding membership. This was a follow up, based on the AGM's agreed proposal that non diagnosed sufferers could become full members of the Society, and why the change was made. Non diagnosed sufferers can now become members of the Society but would only receive certain benefits. To receive full benefits people must join the society - current cost is £20 pa. This did create the most interesting discussion of the day, mainly from members who did not attend the AGM.

The area most contested, was that in the past – people could provisionally join and receive full benefits for 6 months, before deciding whether to become a member of the charity or not. This ruling was therefore not of benefit to sufferers who were trying to get to grips with the disease, and its problems, and needed support from the Society at that stage. Coeliac UK agreed to look at this position.

Miranda Brooks – Volunteers Manager – Tackling Local Group Issues. Miranda's presentation covered 2 areas - how to encourage members to attend local group events and how to persuade members to join their local committees. As we know, the main problem is that Coeliac disease covers all age groups and any event held will not be of interest to all age groups and suit everyone in terms of when you hold the event.

Some suggestions which came during a brain storming session were :-
Cookery Demonstrations / Food Fairs / Dietician Talk / BBQ / Medical Talk / Meals Out / Quiz / Fish & Chip Supper / Outings / Supermarket Dietician Walks / Catering College Meals and Coffee Mornings. ***The Sevenoaks Group have tried quite a number of these over the years but if you would be interested in attending one of the above events please do get in contact with us to discuss further.***

Sponsor Presentations

The sponsors were Glutafin, Juvela and Warburtons. All of these companies stated that they were very willing to support local branches as much as possible. They could support by coming to meetings and events and hold cookery demonstrations / tasting sessions / talks at AGM's or Meetings. All have their own Dietician who could also do a presentation.

There were some practical tips which came out of the presentations:-

- Juvela suggested when making any gluten free pastry to use hard cold fats (lard or margarine) and recommended using Stork for a lactose free diet and butter for a rich pastry.
- Gluten free dough mix **MUST** be kneaded for 2-3 Minutes.
- If you are making hot X buns or tea cakes – before putting into the oven, dip a tea spoon into some vegetable oil and rub the back of the spoon across the top of the dough. It will give a nice sheen when cooked.
- The Warburton's presentation was very company orientated, but they stated that they were the only major front line bread manufacturer, that had invested in gluten free products.

David Apps

Coeliac UK News

Awareness Week – 13-19 May 2013

We're focusing on health for Awareness Week this year with our Gut Feeling campaign.

We're asking the nation to think about whether those symptoms which have been causing a problem are actually coeliac disease. For many of you, we know what the road to diagnosis is like and we hope to find the half a million people who have coeliac disease but don't yet know it.

Social Media

We have seen continued interaction and increased following on our social media platforms over the past month. More of you are joining us too, so if you haven't already, get online and get involved! We have well over 12,000 likes on Facebook and over 7,000 followers on Twitter. If you haven't already *liked* and *followed* us, use the links below to get involved. www.facebook.com/CoeliacUK www.twitter.com/Coeliac_UK

Cost and Access Research Project

Coeliac UK is looking for volunteers from across the UK to take part in a valuable new research project looking at Members' experiences accessing gluten-free foods. This project will build on the Cost Project, which we have been running for the past four years to look at the difference between gluten-free and gluten-containing foods on the supermarket shelves.

The project will be launched in the New Year starting with a basic questionnaire. After that, volunteers will be asked to fill in a short spreadsheet the next time they do their main supermarket shop. We want to know exactly what they can see on the shelves and, possibly more importantly, what they can't see. The questionnaire should only take 15 minutes to complete, but will need to be repeated once a month for a period of six months.

The information gathered will play an important role in our discussions with manufacturers and supermarkets as we work towards improving access to a wider range of products. Coeliac UK will provide detailed instructions, information and support for anybody willing to take part. You don't need any previous experience in volunteering – just a bit of time and plenty of enthusiasm. For more information or to get involved please email volunteering@coeliac.org.uk or write to 'Volunteer Team' at the Coeliac UK office.

Butternut Squash Soup

INGREDIENTS

Serves: 4

- 1 large butternut squash
- 1 medium-large onion
- 500g potatoes
- A few garlic cloves to taste
- Fresh coriander leaves (optional)
- 1 stock cube
- Knob of butter and 30ml olive oil
- 75ml double cream (optional)
- Salt and pepper to taste

METHOD

1. Take the squash and chop off the stalk and flower. Peel with a potato peeler. Chop in half and use a spoon to remove all seeds. Chop into 1 inch cubes.
2. Add the oil and butter to a large pan. Melt the butter on a low heat.
3. Peel & chop the onion. Fry it gently in the pan, with the lid on, until it starts to soften. Keep stirring and checking to make sure the onion doesn't brown.
4. Peel the potatoes and chop into slightly smaller cubes (about 2cm). Add to the onions, ensuring you stir them well to coat with oil.
5. Add the butternut squash. Stir well then cover and cook for 10 minutes, stirring occasionally.
6. After 10 minutes check that the potato has started to soften. When it softens mix the stock with 1 litre of water and add to the pan. Simmer gently and wait until all vegetables are soft. This should take about 15 minutes and you may need to add water - add just enough to cover the vegetables or the soup will be too watery.
7. Add the cream and the coriander leaves (if using). Use a liquidiser or hand blender and liquidise until smooth.



Talkabout

Sevenoaks Area Coeliac Group

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