

Sevenoaks Area Coeliac Group

TALKABOUT

For all your gluten-free gossip, news and events

**November 2016
Edition 40**



Branch Committee

Group Organiser	Fiona Turnbull fi.turnbull@talktalk.net	01474 703869
Secretary	Daphne Paterson dpater2@btinternet.com	01322 863171
Treasurer	Mary Cunnington mary@june-cottage.com	01732 862925
Newsletter Editor	Gill Howe gillieh@tiscali.co.uk	07971 481150
Committee Member	Sally Spike sally.spike214@btinternet.com	01689 828883
Refreshments	Joy Oliver roliver912@googlemail.com	01732 460849
Refreshments	Wendy Gibson wendysheilagibson@yahoo.co.uk	01474 853656
Junior Committee Member	Jessica Howe	

Note from the Editor

Dear Reader

It is with sadness that I write this edition of Talkabout. Our dear friend and committee member, Alison, passed away over the summer. We are thinking of her family and friends at this difficult time and she will be greatly missed by us all.

We will be carrying on with Alison's enthusiasm for baking at this November's meeting where we will be serving tea and homemade cakes following a cookery demonstration and tasting session from gluten free foods representative, Alan Williams. Please come along and join us.

With Christmas approaching, I have included a recipe that will get those creative people out there challenged. I'm going to try it myself and get my daughter's involved too! Have a look on page 12 to see how to make a gluten free gingerbread house.

Don't forget to check the Forthcoming Events page for the November date and times and also get the AGM date in your diary for next year.

As usual, if any of you have any recommendations of places to eat locally please do email them to me at gillieh@tiscali.co.uk.

We hope you enjoy this edition of Talkabout and we hope to see you at one of the forthcoming events.

Gill – The Editor

Gluten-Free Prescribing Debated at Westminster Hall

On Tuesday 1st November, Kevan Jones MP led a debate in the House of Commons on coeliac disease and access to gluten-free prescriptions.

Coeliac UK would like to say a huge thank you to all who contacted their local MP to ask them to attend. There was good attendance by MPs each armed with personal stories. These contributions made for a good debate and intervention on behalf of those with coeliac disease.

Kevan Jones MP described how the disease affects one in every 100 people in the UK, and he himself suffers from it. He then moved to criticise the decision of some clinical commissioning groups (CCGs) to no longer prescribe gluten-free products. Around 40% of CCGs are now choosing to restrict or remove support for patients with coeliac disease. He highlighted there had been a lack of public consultations from CCGs, and the CCGs that have already removed access to prescriptions for gluten-free products have not outlined or implemented policies that offer alternatives to safeguard patients.

Jack Dromey MP and Jim Cunningham MP highlighted that this issue affected older people and younger people respectively, whilst Sir Gerald Howarth MP said the fact that many people inherited the disease from their parents meant costs were spiralling for young families. Kevin Foster MP suggested the provision of vouchers for gluten-free food as a halfway house solution, which the minister said he would consider.

Kevan Jones MP commented that it is the most vulnerable who will suffer from lack of prescriptions and called what some CCGs were doing a "false economy" because one hospital admission would cost more than the annual cost of prescriptions for an individual who adhered to a gluten-free diet. The NHS's existing procurement system was criticised and Kevan Jones MP further called for the return of pharmacy-led supply schemes. Concluding his remarks, he said the issue required urgent intervention.

The Parliamentary Under-Secretary of State for Health, David Mowat MP stated: *“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.”

Coeliac UK will now be following up with the Minister and the MPs who attended and were invited by Members.

If you'd like to read the full transcript, it is available online now at <https://hansard.parliament.uk/Commons/2016-11-01/debates/4BB02B4E-A485-477B-81D9-569AFDDA81ED/CoeliacDiseaseAndPrescriptions>.

If your CCG is restricting gluten-free prescribing, please get in touch with Coeliac UK or visit the ‘campaign with us on prescription’ webpage via the Coeliac UK website.

Alison Batchelor 1950 – 2016

It is with great sadness that we inform you of the death of our committee member Alison Batchelor.

Alison joined the Sevenoaks Voluntary Support Committee in the spring of 2010 and later took on the role of Web Master, sending out regular information emails of news and events to all our Coeliac UK Members. Alison was the contact for all the newly diagnosed coeliac members.



She enjoyed baking cakes for group events and was always coming up with new ideas, especially where our younger members were concerned, helping them ice and decorate their own cupcakes to eat at the children's parties.

Although Alison hadn't been well over the last couple of years she always had a smile for everyone at the signing in table when welcoming members at group meetings.

Alison also enjoyed attending our monthly coffee mornings.

Our very dear friend will be greatly missed.

Forthcoming Events

Please come along to one of our events. We look forward to seeing you soon.

Coffee Morning - Third Saturday of every month

19th November in Tunbridge Wells, there will be no December meeting, 21st January in Sevenoaks, 18th February in Tunbridge Wells, 18th March in Sevenoaks, and 15th April 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. We look forward to seeing you soon - look out for the Crossed Grain magazine on the table and the committee representative will be wearing their blue coeliac t-shirt. 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).

Guest Speaker and Cookery Demonstration

Saturday 26th November – 3–5pm

Christ Church URC Hall, Littlecourt Road, Sevenoaks TN13 2JG

Come along and join us for a Taste & Tester Session with Alan Williams from Gluten Free Foods. Following his session there will be an opportunity to purchase gluten free products at a discounted price if you would like to. We'll also be serving tea and cakes so please stay and enjoy a chat with your fellow coeliacs.

AGM – Saturday 13th May 2017 – 2 - 4pm

Christ Church URC Hall, Littlecourt Road, Sevenoaks TN13 2JG

Please save this date in your diary and we will let you know nearer the time who our guest speaker will be.

My Diagnosis – Sara Newman

I was always a fussy kid when it came to food. I lived on poached egg, a tablespoon of baked beans and a spoonful of mashed potato covered liberally with tomato ketchup. This fitted neatly into a 'Prestige' egg poacher, produced at that time, which made life easy for my Mum and this regime continued until I went to school. At school I avoided school dinners and the mere mention of cabbage sends me into melt down some 50 years later.

At age 7, I was admitted to hospital with symptoms that would follow me for the rest of my life but which at that time baffled the doctors.

I had a lot of stomach pain and would need the toilet immediately! At age 9, I had a small bag to put my soiled knickers in and learnt to change without any fuss. I began to bite my nails. I felt like my body did not belong to me. My weight would fluctuate and I would sometimes feel so tired that I could sleep standing up! I saw so many doctors who blamed it on stress. I could lose a stone in weight in just a few weeks and then put it back on in the same amount of time. I asked for thyroid tests and I just got told I was anaemic. I was depressed. I had SADs. I had three children – what did I expect? Somehow, I had instinctively kept to a low gluten diet.

Then our dog died and one or two other things happened which were life changing events. It was September and my daughter and I decided to go to Disney to cheer ourselves up. Within the first day of arriving, I had eaten Mickey Mouse waffles, had lunch with Winnie the Pooh and Tigger and had hamburger and chips back at our hotel. Not only was I extremely full but I was feeling very sick. During the night I was very ill. I must be the only person that visited Disney and lost weight – I lost 2 stone in as many weeks. This continued until January when even I got alarmed. It did not matter what I ate it seemed to stay a matter of minutes in my body.

A biopsy was suggested as the pain, weight loss and the anaemia could no longer be ignored. Ironically, these were the exact symptoms that I had been admitted to hospital with at age 7 and had been discharged then as having a virus! This time it was finally diagnosed as Coeliac Disease, 50 years later.

The strange thing is that after 50 years, the dashes to the loo are normal and feeling sick after eating gluten by mistake is bearable. The numerous rib breakages are now easier to understand but I just wish someone had listened to me aged 7. The intervening years has led to a bone density issue, a miscarriage that could have been avoided, a daughter who also has gluten issues and being labelled an attention seeker and a number of similar issues.

A major plus has been meeting an amazing consultant who has helped us screen all my children and grandchildren. I do not want them to face the shaming issues I had. Soiling your pants at age 9 is seriously life impacting. My grandchildren are fussy eaters and I say 'so what'!

Going back over the family tree, my Father's family were told not to eat anything white - no bread, no pasta and no pastry – sound familiar? Unfortunately, during the depression they had to eat bread and jam and suffered terrible bone deformities of their spine and my grandmother lost twins to malnutrition but now we suspect it was gluten and lactose issues. Lactose is what I am addressing now. This is a serious issue and if only I had known earlier it could have been very different for me but then the markers were there for all to see in our family many generations ago!

Sevenoaks Voluntary Group

The current committee have been working together for around 11 years with some members joining and some departing. We are a group of volunteers who are committed to improving the lives of people in our area with coeliac disease.

We have seen many changes over the years, most of them for the better, such as improved food labelling so that we know which allergens are present in products. In the past, I have spent many an hour in supermarkets reading food labels!

Eating out is so much easier as many restaurants and pubs now offer a gluten free choice and sometimes whole menus, which is fantastic. Of course, we should still be vigilant with checking about cross contamination as this is still a problem in some eateries! Remember too that it is now required by law, for anyone who sells food products, to have a list of what ingredients are in the food they are selling.

We have tried to keep abreast of changes that might interest our local members and share them with you via Talkabout or at group meetings but your feedback is always useful if you feel there are other ways that we can help.

We still run a monthly coffee morning which we felt was one of the most important aspects for newly diagnosed coeliacs. The first few months of diagnosis can be very daunting and to talk to others who are used to coping with a gluten free diet is very helpful. However, now that there is a lot more information available and eating out is easier do we still need to run a monthly coffee morning or could it be bi-monthly? Please tell us your thoughts as it is a big commitment for Daphne who currently runs our coffee mornings and has been doing so for the last 10 years! We will be sharing the load between the committee members over the next 12 months so if any of you are a regular to our coffee mornings please look for one of us; we will be wearing our blue coeliac t-shirts.

Although we are called the Sevenoaks Voluntary Group, our remit covers a huge area and we are conscious of the fact that we currently run most of our bigger events in Sevenoaks. Please let us know if it would be beneficial to you if we ran an event once a year somewhere else. Perhaps Tonbridge or Tunbridge Wells? If you have any ideas for a venue this would be greatly appreciated as finding a hall that can accommodate us at a reasonable hire rate is also a challenge. Please email or call one of us with any feedback or ideas for location and venue. Our email addresses can be found on page 3 of this edition.

Finally, I am very proud and delighted to say that this is our 40th issue of Talkabout! I really didn't think it would still be going when I suggested the idea over 10 years ago! I hope you all continue to enjoy reading it and please let us know if we can improve it in any way.

Please Help Us New Member Secretary Required

Following the very sad news of Alison's death, we find ourselves in need of some help. Alison was the New Members Secretary and she would send out a welcome letter to any newly diagnosed Coeliacs in our area, who joined Coeliac UK, to let them know about the local group and how we could help them. Therefore, we are looking for a person who would like to help the local group by spending an hour or so a month checking the database and sending out a standard welcome letter or email to our new members. It isn't a big job but can be very rewarding so please consider dropping us a line if you'd like to find out a bit more before committing to it. We'd love to hear from you. Please contact Fiona Turnbull on fi.turnbull@talktalk.net if you feel you could help us with this.

Gingerbread House Recipe



Ingredients

225g (8oz) root ginger
225g (8oz) white sugar
225g (8oz) demerara sugar
225g (8oz) unsalted butter
500g (1lb 10oz) gluten-free white plain flour*
1 tsp cream of tartar
500g (1lb 10oz) unrefined icing sugar
4 egg whites
1 gingerbread house mould (you can buy on ebay or amazon)
1 x 12 inch square cake stand
Piping bag for icing sugar

Method

- Peel root ginger, boil until tender, add white sugar and boil until syrupy.
- Chop crystallized ginger up in food processor.
- Preheat oven to 160°C/320°F/Gas Mark 3.
- Melt butter. Add ginger. Combine together with flour and cream of tartar in bowl.

- Add flour slowly until right consistency, not too runny.
- Put the moulds onto 2 trays to support them. Spoon the mixture into the moulds and place in preheated oven for 25 to 35 minutes until firm to touch. Leave until cold.
- Whisk 4 egg whites and combine with unrefined icing sugar until smooth.
- Pipe icing sugar onto bottoms and sides of gingerbread house walls and place on cake stand. Support with a glass until firm and dry.
- Pipe icing sugar onto sides of roof.
- Take away glass and stick 2 roof sides onto house.
- Pipe icing sugar onto bottoms of little gingerbread men and tree and place in front of house. Pipe icing down sides of roof and decorate to personal taste and leave to set and dry and Voila!

Note from the Editor

If anyone tries this Gingerbread House, please can you send me a photo of your creation because I'd love to see them and put them in the next edition of Talkabout. I'm going to try it over Christmas too!

Myths About Coeliac Disease

'Coeliac disease is rare'...myth

Research shows that coeliac disease affects 1 in 100 people in the UK, making it much more common than previously thought. Under diagnosis is a big problem and research suggests around 500,000 people have not yet been diagnosed.

'Coeliac disease is a food allergy'...myth

Coeliac disease is not a food allergy or an intolerance, it is an autoimmune disease. In coeliac disease, eating gluten causes the lining of the small intestine to become damaged. Other parts of the body may be affected.

'You have to have gut symptoms such as diarrhoea to have coeliac disease'...myth

Coeliac disease is known as a 'multi-system' disorder - symptoms can affect any area of the body. Symptoms differ between individuals in terms of type and severity.

'Only children get coeliac disease'...myth

Coeliac disease can develop and be diagnosed at any age. It may develop after weaning onto cereals that contain gluten, in old age or any time in between. Coeliac disease is most frequently diagnosed in people aged 40-60 years old. Delayed diagnosis is common and our research shows the average time it takes to be diagnosed is 13 years.

'You have to be underweight to have undiagnosed coeliac disease'...myth

Recent research suggests that most people with coeliac disease are of normal weight or overweight at diagnosis. Body weight alone should not be used to decide whether or not you should be tested for coeliac disease.

'You can 'grow out' of having coeliac disease'...myth

Coeliac disease is a lifelong condition. The gluten-free diet is the only treatment for coeliac disease. If gluten is introduced back into the diet at a later date, the immune system will react and the gut lining will become damaged again.

If someone following a gluten-free diet is retested for coeliac disease (antibody blood test, gut biopsy) it would be expected that the tests are negative. This means they are responding well to the gluten-free diet. There are no antibodies in the blood because there is no gluten for the immune system to react against. Taking gluten out of the diet allows the gut to heal.

'A breadcrumb won't hurt someone with coeliac disease'...myth

Even very small amounts of gluten can be damaging to people with coeliac disease. Therefore, taking sensible steps to avoid cross contamination with gluten is important.

Top tips include:

- Keep cooking utensils separate during food preparation and cooking.*
- Avoid frying food in the same oil that has previously been used to cook foods which contain gluten.*
- Use a clean grill, separate toaster or toaster bags to make gluten-free toast.*
- Use separate breadboards and wash surfaces thoroughly.*
- Use separate condiments like jam, butter, mustard and mayonnaise.*

'Coeliac disease only affects people of European origin'...myth

Coeliac disease affects all ethnic groups and is common in Europe and North America, as well as in Southern Asia, the Middle East, North Africa and South America.



Talkabout

Sevenoaks Area Coeliac Group

Please send your letters or enquiries to:

**Gill Howe at Rochdale, 335 Main Road,
Westerham Hill, Kent TN16 2HP**

Email: gillieh@tiscali.co.uk