



West Sussex
Local Group

WEST SUSSEX COELIAC GROUP

Newsletter – January 2018

WELCOME

We hope all enjoyed a good gluten free Christmas and that your New Year has started well. In this Newsletter, we are pleased to let you know about all the things that are already planned to take place during 2018.

In addition to our regular gatherings, there will be special events throughout the year, starting with our AGM in March where we have arranged for a guest speaker / cookery demonstration, as your Questionnaires last year indicated these were of interest. More details, including the Meeting Agenda are shown below and Minutes from the 2017 AGM can be seen at the end of the Newsletter. We look forward to seeing as many of you as possible at this year's AGM!

Then in May, to mark Coeliac UK celebrating their 50th birthday, we will be holding a special Big Birthday Fun Day in the week leading up to our Awareness Week. And later this year there will be our second Food Fair, which proved so popular in 2016. More details below, and make sure to add the dates to your diary!

2018 AGM

COELIAC UK WEST SUSSEX LOCAL GROUP

AGM

Saturday 10th March 2018 from 2.15 to 4.30 pm

Pulborough Village Hall, Swan View, Pulborough RH20 2BF

AGENDA

- Welcome and Introduction
- Apologies for absence
- Highlights for 2017 and Future Plans : Anna Henderson, Group Organiser
- Group Finances : John Johnson, Treasurer
- Election of committee members
- Questions
- Any other business
- Close

The AGM will be followed by tea and coffee and a talk on Healthy Gluten Free Eating and a cookery demonstration by Melanie Luckes, a trained chef, Medical Herbalist, Nutritionist, and Homeopath, with her own Wellbeing Clinic, Health school and café Luckes in North Street, Chichester. She is also a Coeliac.

Please let us know if you wish to attend so we have an idea of numbers. We would be grateful for any donations of cakes/biscuits to be sold at teatime in aid of Group funds. Please let us know what you will be bringing and please provide a clear list of ingredients for display.

We would also welcome help with setting up and serving refreshments, please contact Pam Whittaker at andypam.whittaker@btinternet.com

All the Committee are up for re-election. We always have room for more and particularly would welcome applicants with experience in marketing and publicity and/or who would like to progress a programme of activities for our younger members. Should you have any nominations for yourself or anyone else, please email/write to Tracey Martin at: traceym510@gmail.com / 10 Sandeman Way, Horsham, RH13 6EL.

COELIAC UK BIG BIRTHDAY FUN DAY

Saturday 5th May at Butlins, Upper Bognor Road, Bognor Regis, PO21 1JJ **from 10 am**.

A Celebration Lunch and Fun Day has been organised at Butlins Bognor by the West Sussex local Group for Coeliacs of all ages and their families to celebrate 50 years of Coeliac UK. Coeliac events end at 4pm, but you may continue to enjoy Butlins entertainment until 8pm.

£19 per person (£11 child 2 to 14) includes:

- all the Butlins entertainment accessed by a Day Pass (see Butlins link: www.butlins.com/day-visits/bognor-regis/index.aspx)
- 3 course hot/cold celebration GF buffet lunch (child menu for children)
- tea/cupcake at teatime.
- GF samples to take home

NB parking is not available on site, use nearby public car parks.

Booking essential and numbers are limited; booking closes 28th February.

Please email Anna Henderson at westsussexcoeliacgroup@hotmail.co.uk to reserve your places, then pay online by 28th February to sort code 30-94-28 account number 63203368, reference "Butlins Day". Alternatively write to her enclosing an SAE and cheque for the number of tickets required, at 155 Barrack Lane, Bognor Regis PO21 4ED. Please make cheque payable to "Coeliac UK - West Sussex" and write "Butlins Day" on the back.

This price is an incredible saving on the usual cost of over £50 per person as we want as many as possible to enjoy this special day but if it's too expensive for you or your family, do contact Anna as we may be able to assist. 0771 267 6933.

We would be grateful for a little help on the day such as putting out the cakes and displaying the samples. Please let Anna know if you are able to help.

GLUTEN FREE FOOD FAIR

Saturday 6th October at Boxgrove Village Hall, The Street, Boxgrove, Chichester, PO18 0EE **from 10 am to 2 pm**.

We are delighted to be holding the 2nd Coeliac UK West Sussex Local Group Food Fair this year. Come along for all things Gluten Free!

We could do with your help in the preparation/leafleting/on the day. If you would like to volunteer – even an hour would be so helpful - please contact Pam Whittaker at andypam.whittaker@btinternet.com

REGULAR EVENTS

The following events are also taking place during 2018:

CHICHESTER Coffee Morning at Wild Mint Café, House of Fraser, West Street, Chichester PO19 1QG from 10 to 11 am.

Wednesday 7th February | Thursday 24th May | Wednesday 5th September

HASSOCKS Coffee Morning / Brunch at The Barn Restaurant, South Downs Nurseries, Brighton Road, Hassocks BN6 9LY from 9.30 to 11.00 am.

Saturdays: 17th February | 16th June | 15th September

WORTHING Coffee Morning at Food Restaurant, 6-8 New Street, Worthing BN11 3B from 10 to 11.30 am.

Tuesdays: 13th February | 13th March | 10th April | 8th May | 12th June | 10th July | 14th August | 11th September | 9th October | 13th November

Looking ahead – Who misses Chinese food? The Lion, Pagham have now offered to cook us a GF Chinese meal! Email Anna if you would like to be included.

Photograph Consent – photographs will be taken at all events and may be used on our website, social media, publications and other promotional material, exclusively to promote the work of Coeliac UK in helping people to live gluten free through fundraising, research, campaigning and membership support. If you do not wish your or your child's photo to be taken, please let the organiser know when you arrive at the event.

PASS IT ON!

It's great when Members share recommendations for venues in West Sussex serving gluten free food, or other useful tips. We are grateful to all those who have contributed over the last few months, as detailed below:

- If you are in London looking for GF food - two possible venues:
 - NICHE RESTAURANT in Angel Islington, London. 100% GF restaurant - gives a great feeling being able to choose anything on the menu. Good service. 'We will be going back'. www.nichefoodanddrink.com/
 - BEYOND BREAD - GF bakery, Charlotte Place, Near Goodge Street underground. Sandwiches, toasties, fabulous cake all GF. A real find. They also have a branch in Upper Street Islington. www.beyondbread.co.uk/
- FACEBOOK PAGE: Coeliacs Eat out too - good for eating out tips
- M&S 'DINE IN FOR £10 FOR 2' has featured GF options including Lasagne - plus GF puddings. And check out the M&S new super seeded rolls - delicious!
- Woodmans Arms, Hammerpot, Angmering
- Fox goes Free, Chichester
- Wild Mint Café, House of Fraser, Chichester
- Purchases, Chichester
- Cote Brasserie, Chichester
- Ides Restaurant, Aldsworth Avenue, Goring. Excellent GF menu.
- Sussex Oak, Warnham. - good GF choices throughout the menus - very helpful service - look out for the Toblerone cake!!

- Shoreham Airport - very helpful - understand the GF diet.
- WEBSITE: CoeliacSanctuary.co.uk -a good place for Coeliac information, gluten free recipes, places to eat, reviews and product guide. They also sell Multi allergen Coeliac Travel cards (explaining Coeliac Disease in different languages) and Gluten Free stickers to label your food.
- Mama Gamouche, Hassocks
- Thatched Inn, Hassocks
- HOLIDAYS: extra baggage allowance permitted for Coeliacs with airline on production of doctor's certificate that you are a diagnosed Coeliac and need to eat a gluten free diet for life. Contact airline passenger assist in advance of flight to advise.

STAY IN TOUCH

We would love to receive your contributions, news, recipes, local information or recommendations, suggestions for events or how we may better provide support for you, to be shared with others in future newsletters or via our social media pages. Please do send them to us.

You can keep in touch with what's going on, or contact the West Sussex Coeliac Group by

E mail - westsussex@coeliac.org.uk

Website - www.coeliac.org.uk/local-groups/west-sussex/

Facebook – www.facebook.com/westsussexcoeliacuk/

Twitter - www.twitter.com/CoeliacWSussex

Our preferred method of contact is by email. If you do not have e mail, we would encourage you to provide the email of a family member or friend or neighbour. We often receive very short notice of events and do not have the manpower to send out letters in time. We do not want you to miss out!

Please ensure all your details on the Coeliac UK website are up to date. You can check them on line at www.coeliac.org.uk or telephone Coeliac UK on 0333 332 2033. If you no longer wish to receive communications from us, please amend your details on the Coeliac UK website.

The personal information that you have provided will be used by West Sussex Coeliac Group for the administration of and fundraising objectives of the charity and for no other purpose.

2017 AGM MINUTES

West Sussex Coeliac UK
Annual General Meeting
Saturday 11 February 2017 at 14.30-16.30
held at The Kings Church, 33-35 Victoria Road, Burgess Hill, RH15 9LR

MINUTES

1	<p><u>Welcome, Apologies and Minutes of 2016 AGM</u> Bill Andrews (BA) welcomed 19 coeliacs, 8 guests and Miranda Brooks from Coeliac UK to the meeting. There had been one apology from Jan Millyard.</p> <p>The minutes for the 2016 AGM were approved and signed as true record of the meeting.</p>
2	<p><u>Miranda Brooks (MB) talk</u> MB has been working in the volunteering team for 9 years providing support and training to the local groups. Coeliac UK has changed its logo after 18 month consultation which had</p>

highlighted a lack of perception in linking between the Coeliac UK and the crossed grain symbol. The old strapline of Support, Campaign and Research has been changed to the more meaningful Live Well Gluten Free. The new logo would always be seen with the 3 accreditation logos to enforce the link.

The website has been updated. The venue guide section is now much easier to use and includes accredited venues that have had the Coeliac UK training; member recommendations and venue's used by local groups (marked by LG). The recipe database contains over 6000 recipes which have been tested and approved in house. These have come from Crossed Grain; members and manufacturers.

Most work in recent years has been on the 'Is It Coeliac' campaign trying to find the five hundred thousand undiagnosed coeliacs. Launched in 2015 this campaign was sponsored by Thermo Fister(?) who donated £168,000. The first TV advert was seen by 9 million during daytime TV and on the website. A screen website was set up asking questions on medical history and providing a written report to take to GP. Fifty thousand people have taken this self-assessment. Leaflets were sent to 6000 GP's surgeries and in April/May 2015 & 2016 adverts were placed on GP's screens in surgeries. 5000 leaflets were also handed out in several large towns with on-site assessments of 500 people results in 17% going forward for medical diagnosis. This campaign was picked up by the media with 1 million views during Awareness Week and 117 positive national news stories. Considered such a success, the sponsors now wish to roll the campaign out throughout Europe. Coeliac UK is the largest coeliac group in Europe and is a world leader in terms of research.

This work could not be carried out without volunteers. Coeliac UK partnered with pharmacies and patients referred for low iron or IBS being tested for coeliac condition. A Gov UK poll carried out in 2015 showed a poor awareness of gluten free lifestyle, repeated again in 2016 there was a 5% rise in awareness. The poll will be repeated in 2017.

In 2017, they are carrying on with the 'Is It Coeliac' campaign. Awareness week will be concentrating on GF revolution with an emphasis on food when eating out or travelling. Areas of interest are Hospitals (only 2-3 are accredited); planes; trains; motorway service stations and take aways.

The ducks are coming for awareness week (8-14 May) – in a link with RSPCA that you are not supposed to feed ducks with bread. Caroline Quentin is again supporting the week.

The fight on prescription cuts/reductions is continuing. A legal challenge has recently been made on the stopping of prescriptions in Somerset. This challenge has resulted in a review of the decision. The NHS in Vale of York recently extended to 6 month a pilot voucher scheme where £15 per month could be spent on gluten free food in Co-op; Morrisons or M&S. The NICE guidelines for the coeliac condition released in November stated "the use of prescriptions is an important part of the treatment of coeliac condition". A Parliamentary Debate in November acknowledged the post code lottery cuts and reductions to prescriptions was unacceptable and that consultation often inadequate. These situations should be highlighted and reviewed.

The volunteer local groups continue to be important. Currently 80 local groups with 2 new ones currently being formed. Manufacturers like to provide information/food for free market research. Some additional roles were identified: Health Campaigner –working mainly in hospitals; the Food Campaigner working with restaurants; manufacturers and chefs; the member to member mentoring particularly useful if a new condition is added to the coeliac condition and the Case Studies which is always looking for members to be media studies.

	<p>2018 will be the 50th birthday of Coeliac UK.</p>
3	<p><u>Group Organiser Report</u> BA highlighted the changes happening around Coeliac UK; the building we met in being redeveloped and the Crossed Grain. After 5 years, he is standing down as Organiser.</p> <p>There are 728 members on the group database, as there was when the group started 5 years ago. Maggie Brackpool had been at the first committee meeting and has stayed a committee member until today. Several others had been on the committee but not at the meeting. Since then there had been 23 other committee members.</p> <p>2016 for BA had been spent supporting a friend in hospital in London and he had come across problems finding gluten free food when you were just a visitor.</p> <p>During Awareness Week there had been 2 stands in our local hospitals (Princess Royal, Haywards Heath & Worthing). There had been a leaflet drop by one member. Despite a targeted mailshot to those within 10 miles, the walk at Abingerworth had not been well supported but still managed to raise £2300.</p> <p>A competition in the newsletter offering bottles of beer had resulted in nil response; only 1 person was interested in the AEG steam oven demonstration and there had been no response to the request for ideas for future events.</p> <p>The food fair had gone well and some suppliers had already been in touch asking if it would be repeated. There had been three meals organised in the run up to Christmas (Pagham, Worthing and Rustington). Voluntary Action Worthing had teamed up with CCG to pilot a scheme getting the group's details on the screens at GP's surgeries. The CCG in West Sussex is split into four regions. The coastal section is not expecting any changes to prescription levels. However the Horsham; Crawley; Mid Sussex and High Weald had recently merged with Brighton & Hove and East Surrey. Brighton & Hove & East Surrey areas had had drastic prescription changes and so there was a concern this could spread.</p> <p>More support was needed to help with coffee mornings at Hassocks and Bognor/Chichester areas.</p>
4	<p><u>Group Treasurer's Report</u> Raffles and Tombola's had bought in -£241.22 Donations - £58.35 Newsletters sent by post - £18 Food Fair profit - £1402.22. Total Income - £1746.79</p> <p>Expenses of post, printing, stationery and hall hire were £326.08.</p> <p>The current balance in the Lloyds bank account is £2,663.65 however the Committee had at the last meeting agreed to donate £500 to Coeliac UK (cheque given to MB at meeting) and the money raised at Pagham Christmas meal £121 was for research purposes.</p> <p>Leaving a total balance of £2002.65</p>
5	<p><u>Election of Officials and new Committee</u> As elections are only for a year, the old committee were stood down after being thanked for their service. MB highlighted the work over 5 years by BA as organiser. The East and West Sussex groups had been set up in 2012 but the East Sussex group had folded again by 2014. BA had been a strong leader and driver in the success of the West Sussex Group and would be</p>

	<p>missed at Coeliac UK. Anna Henderson presented BA with beer and flowers to his wife and other retiring committee members.</p> <p>Elections were then held to the following posts: Group Organiser - Anna Henderson (proposed Pam Whittaker; seconded Hilary Marfleet). Group Treasurer – John Johnson (proposed Pam Whittaker; seconded Tracy Martin) Group Secretary – Tracy Martin (proposed Hilary Marfleet; seconded Pam Whittaker)</p> <p>The new committee (proposed by Margaret Mercer and seconded by John Johnson) are: Nicky Johnson Andy Whittaker Pam Whittaker Chris Martin Jenny Martin Phillipa Caddy</p>
6	<p><u>Future Events</u> Planned so far are: Worthing Coffee morning at Food – Tuesday 14 February Chichester (John Lewis) 10.00-11.30 coffee morning – Monday 27 February Hassocks (South Downs Nursery) breakfast/coffee – Saturday 19 March</p> <p>MB highlighted the long lead in time to get events printed in Crossed Grain. Submission by the end of February for the next edition in May.</p>
7	<p><u>Any Other Business.</u></p> <ul style="list-style-type: none"> ➤ Trixie offered to help source alternative venue’s in Hassocks area. ➤ A questionnaire would be issued by new committee in due course seeking information from members on events/support needed ➤ It was felt that more advertising of events was needed in free magazines. However in recent years, adverts had been removed as editors felt they counted as free adverts for the business rather than the group. ➤ MB highlighted that Coeliac UK have a membership list which is kept updated of Coeliac UK members. The local group may have additional people. 28 days notice should be given of events and can be added to the website where it should be picked up automatically for the monthly newsletter. <p>The meeting then closed with MB thanking all for attending.</p>