SOUTH SURREY LOCAL GROUP NEWSLETTER

Spring 2019

PRESCRIPTION UPDATE

Having in the past tried to help with enquiries members concerning bread mixes discovered when I presented my prescription last to pharmacy, they told me I could not get Bread mixes. I contacted Coeliac UK for an update and was told: the Dept. of Health and the Local Commissioning Group both say we can get fresh bread and rolls, longlife bread and rolls PLUS various bread mixes, including Juvela, Glutafin and Barkat. After guite a standoff the pharmacist printed off the PSNC's document and discovered YES we can get bread mixes. If you have any difficulty pharmacies and surgeries need to look at the PSNC's document psnc.org.uk. It gives advice and the list of prescriptible items which came into force 4th Dec 2018.

Helen Searle

E: southsurrey@coeliac.org.uk
@SSurreyGroup
@SouthSurreyCoeliacUK
Helpline: 0333 332 2033

COELIAC UK AWARENESS WEEK 13th - 19th May 2019

Group Organiser's Report

coelia

Hello to all our members and a special welcome to those who have recently joined us.

South Surreγ Local Group

Welcome to our Spring 2019 Newsletter. I hope you have managed to avoid colds and flu.

It has been a more difficult and stressful year, due to GDPR which has caused trouble with some members having difficulty booking events. All local groups have to follow instructions from Coeliac UK, but I am aware not everyone has a computer or email address.

Sarah Sleet CEO of Coeliac UK has resigned as well as Miranda and Garry our Coeliac UK volunteers who liaise with us when we need advice. Mandy Carey is now our volunteer person

Now for important business. This may be the last S Surrey newsletter and the disbanding of the S Surrey group.

We are desperate for committee members.

Jon is standing down as secretary to help set up a North Surrey group. We also need committee members to help the existing committee.

The job of the secretary does not have to be one person; the work can be divided up. Jon is more than willing to help.

Mike, our treasurer, is willing to stand for one more year, heartfelt thanks, Mike.

My thanks to all of the committee for their hard work and dedication. PLEASE help us keep South Surrey going.

Helen Searle

Your Coeliac UK Membership

The South Surrey Group is a local support group for Members of Coeliac UK; your membership needs to be renewed annually. The cost is \pounds 24.00 per year (\pounds 12 annual concessionary rate is available to select for those on a reduced income. For example, those registered unemployed, students and those reliant on state pensions or benefits). Without a current membership you will miss out on the Crossed Grain magazine and the Food Directory and smartphone app, which is a great help to identifying companies and products which are gluten-free. Unfortunately, due to the cost of hard copies of the newsletter and postage, we will only send newsletters by post to those who have a current membership of Coeliac UK and no access to email.

Our preferred method of contact is by email. If you do not have email, 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 human resources to send out letters in time. We wouldn't want anyone missing out!

We also try to arrange social get-togethers such as group meals at restaurants (see below for the Calendar of Events 2018). **Remember all this is included with Coeliac UK membership!**

Please ensure all your details on the Coeliac UK website are up to date. You can check them online 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.

Do we have your correct email address? If you are receiving this newsletter as a printed copy and you have access to an email address, please let us know. We can save costs by sending future newsletters to you by email. Don't delay update your details now at <u>southsurrey@coeliac.org.uk</u>

Events since the last newsletter

Pub Lunch at The Barley Mow

On Saturday 8th September 2018, South Surrey Coeliac Local Group arranged for a pub lunch at a nonaccredited but coeliac knowledgeable pub in Tandridge, Surrey. The plan was to sit in the beer garden

where the management of the pub have an array of outdoor pub games for children and adults alike. Sadly, the weather albeit dry, was overcast and a little chilly, so we were provided with a large banquet style table in the lower room of the main pub. There was a set menu of 3 starters, 3 mains and 3 desserts to choose from on this occasion (the pub has a larger GF menu) and this appeared to cater for everyone's needs of the 12 people that attended. It was lovely to welcome some of our newer members (one diagnosed as recently as 2 weeks prior to the event), who said the event was both informative and welcoming. We shared recipes, experiences and

recommendations on topics such as prescriptions, supermarket products and eating out with friends. Positive feedback was given, including from our younger members....

'12 people were at the Barley Mow Pub for a GF lunch. There were 4 children..... It would be more fun if there were a few more kids next time'. (NANCY age 8)

'The burgers were really tasty.....' (TOBY age 7)

'I liked meeting the other children and eating the chocolate brownie!' (LIBBY age 5)

Good conversation and tasty food were enjoyed in the cosy surroundings of this delightful country style pub. Please visit <u>http://barleymowtandridge.com</u> if you require more information on the pub.

Kirsty Cranefield

Autumn Meeting

On Saturday 13th October 2018, South Surrey Coeliac Local Group had its Autumn Meeting at Rudgwick Village Hall. The general meeting was very informative:

- reviewing the events held during the year
- outlining progress made on educating companies and organisations (including Butlins, M&S Guildford, Royal Surrey County Hospital and Woodcote Green Garden Centre) as to provisions needed for coeliac. Liz Toft (dietitian) announced that RSCH now has a comprehensive G/F menu. Also the main menu is marked with G/F and vegetarian options. It has taken a long time and perseverance, but we got there at last.
- explaining changes brought in by head office (including the dreaded GDPR and IT changes!) and,



discussing and sharing experiences with prescriptions in various areas across Surrey. Many desire the
flour mix rather than bread but are battling their GPs to get it, while others are battling to get anything
at all. Some useful tips were shared, including writing to the GP giving reasons why you require a certain
GF bread/flour/roll product that is available on the NHS but not currently offered by the clinical
commission in your area. This has proven successful for some SSC members, so fingers crossed it works
for others!



Afterwards, attendees were treated to an array of homemade cakes baked by the Committee accompanied by a cup of tea and a light-hearted but interesting talk from Jim Glover (High Sheriff of Surrey 2018-19). The room was filled with amazed faces as he talked us through the history, traditions, costume and responsibilities of the role. There were a few chuckles along the way as Jim had some cheeky tales to tell too! What was refreshing was hearing him talk about his experience of being a coeliac while fulfilling his current role.

For more information about Jim and the role of High Sheriff of Surrey, please visit <u>www.highsheriffofsurrey.com</u> where you will find Jim's blog about his visit to the meeting.

Kirsty Cranefield

Christmas Lunch 1^{st} December 2018 held at Clandon Regis Golf Club

This was the fourth year we had joined the Group for the Christmas Lunch at the Golf Club and have to say we weren't disappointed. A lovely warm welcome when we arrived, time for a drink and a catch up before lunch. The dining room was beautifully dressed, the tables looking wonderful. The menu offered a wide choice of starters, mains and desserts, all delicious and well presented. Good service also helps to make a meal more enjoyable, and the staff excelled. We finished with coffee and mints while the raffle was drawn; it is a great location, the meal was great, and it was a great start to our Christmas celebrations.



Maria & John Bird

Jolly Cooper Pub Lunch

The pub lunch held at the Jolly Cooper Pub (Epsom) on Saturday 9th February, was a delightful opportunity to enjoy a tasty and varied GF menu with the good chatter of fellow Coeliac UK members. Numbers crept

as high as 27 in attendance on the day and perhaps even more pleasing was the number of North Surrey Coeliac that we welcomed, reflecting our group's efforts to reach out and offer support to the North Surrey members while the North Surrey Local Group is being launched.

We received some lovely feedback, one attendee wrote, ".....*The food was excellent and very reassuringly GF"*..... While another wrote, "*A big thank you for organising the lunch at the Jolly Cooper's today*....... *I had a great time meeting and talking with new people, as well as enjoying the food*."

They say actions speak louder than words and I think the smiles in this picture say it all.

Restaurant Recommendations

The Jovial Sailor, London Road, Ripley GU23 6EZ

Formerly in the Chef & Brewer chain, in January 2019 it re-opened under a smaller group (Barons Pubs). It offers a wide menu (with dietary requirements and advice available), and when I informed them of my Coeliac diagnosis they were even more attentive! For all members who are very concerned about cross contamination, when I asked about ordering ham, eggs and chips, they did tell me that they used the fryer for non gluten-free items also. However, since being diagnosed in 1981 I have not personally had any problem with this (and still here to tell the tale!), so I leave any decision about this to the individual (and the meal was delicious, and I can report that I didn't suffer any after effects!).

Chris Sansom

Deep Blue, fish shop in Bridge St. Godalming now have G/F fish and chips every Monday.

Helen Searle



Kirsty Cranefield

Top Tips for our newly diagnosed members (2nd Edition)

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Childhood bug could trigger gluten misery

By Ben Spencer Medical Correspondent

A CONDITION which leaves victims unable to eat bread, pasta and other foods containing gluten could be triggered by a tummy bug in childhood, research suggests.

Mystery has always surrounded the cause of coeliac disease – a common digestive problem.

But experts now believe it is triggered by enterovirus, which strikes in childhood. They say this discovery could pave the way for a vaccine which could protect against coeliac disease. Roughly one in every 100 Britons has the

Roughly one in every 100 Britons has the condition, the only treatment for which is a life without gluten.

This protein, usually derived from wheat, is found in pasta, most types of bread, breakfast cereals, biscuits and cakes, and can cause stomach upsets,

'Vaccination could reduce the risk'

fatigue and more serious problems for coeliacs. Experts from the Norwegian Institute of Public Health tracked 220 children from the age of three months until they were ten years old.

Each had genes which make them vulnerable to coeliac disease – carried by 40 per cent of the population.

During the decade of monitoring, 25 were diagnosed with coeliac disease and researchers found they were 49 per cent more likely to have had enterovirus.

Writing in the British Medical Journal, they admitted far more work is needed to prove their findings.

But they added: 'If enterovirus is confirmed as a trigger factor, vaccination could reduce the risk of development of coeliac disease.' In this edition I would like to focus on tips for providing for Coeliac children. I am proud to say that my daughter is a popular girl with lots of friends and with that comes lots of parties and invitations for dinner. For her it is great – for me as her mother, it started out as very stressful after her diagnosis.

My rule of thumb now is to provide my daughter with food to take with her in a lunch box. Most parents are very understanding and even relieved when I offer to do this – it takes the pressure and responsibility off them. So, I ask what food is being served to the other children and make something as similar as possible that is GF. If there is going to be crudities and fruit platters put out, I also provide that in her lunch box as cross-contamination of Gluten runs rife on a buffet and kids are the worst for diving in with sticky glutenous fingers!!

I sit my daughter at the end of a table whenever possible, so there is the least chance of gluten crumbs being passed over her plate by others.

Some squashes are 'Fruit and Barley', and these are not suitable for Coeliac, so I always check what drinks are going to be offered and provide an alternative if necessary. I prefer she drinks from a carton at parties as the drink is then enclosed and protected from glutenous crumbs from the children around her.

If your child is school age, the school kitchen is required to provide for special dietary requirements, but that does not mean to say they have the facilities to avoid cross-contamination. My daughter does not have school dinners because of this. There are booklets available to download off Coeliac UK website which can give parents and schools advice.

https://www.coeliac.org.uk/document-library/4356-school-pack-information-forschools-in-england/?return=/gluten-free-diet-and-lifestyle/school-meals/

https://www.coeliac.org.uk/document-library/4358-school-pack-information-forparents-in-england/?return=/gluten-free-diet-and-lifestyle/school-meals/

https://www.coeliac.org.uk/gluten-free-diet-and-lifestyle/school-meals/

An Individual Health Care Plan is recommended to be written by the school in consultation with parents. One can be downloaded as a template from the Coeliac UK website.

https://www.coeliac.org.uk/document-library/1616-individual-healthcareplan/?return=/gluten-free-diet-and-lifestyle/school-meals/

At schools, there are always birthdays, reward activities and end of term parties that involve the pupils being given food other than their lunch. I provide some pre-wrapped GF goodies for the class teacher to stash away and give to our daughter as and when the occasion arises.

Cooking is another activity that occurs in schools, especially in Reception and Key Stage 1, and once again clear communication is needed with the school, so the necessary GF ingredients and conditions are provided. My daughter is always in the first cooking group of the day before the kitchen/cooking table gets contaminated and I am provided with the recipe and ingredients list so I can check what GF alternatives need to be provided.

Resources are another surprise in schools – Play-Doh, Dried pasta or cereal for art and counting in maths, food added to the sensory table or water tray for affect.... I had to sit down with the class teacher and highlight the need for precautions not just to do with eating.

Kirsty Cranefield

Our planned events for 2019

Date & Time	Event	Location
27 th April at 14:00	AGM with Speaker (see below) Tea and cake to follow	Rudgwick Village Hall, West Sussex RH12 3JJ
18 th May at 19:00	Quiz Night with food but no alcohol permitted	Merrow Methodist Church Hall Guildford
29 th June time 15:00 – 16:30	Children's Magic Lesson with drink and snack (ages 5- 12)	Farncombe Youth Football Clubhouse, GU7 3RZ
10 th August at 12:30	Summer BBQ	Clandon Regis Golf Club, Guildford GU4 7TT
18 th August time tba	Families Picnic and Soap Box Race 2019	Farnham Park, castle Street Farnham
12 th October	Autumn Members Meeting with Speaker from Barkat	tba
4 th December at 18:00-19:00	Teenagers Rock climbing at the Spectrum. £13.50 per child.	Guildford Spectrum, Parkway, GU1 1UP
7th December time tba	Christmas Lunch	Clandon Regis Golf Club, Guildford GU4 7TT

Please use the booking forms attached (or download from https://www.coeliac.org.uk/local-groups/southsurrey/documents/) if you are interested in attending any of the events. If you have any ideas or would like to plan an event please email us at southsurrey@coeliac.org.uk

AGM April 2019- Guest speaker is Erica Dore

Last year, I retired, having spent the whole of my working life as a radiographer. One of the specialty areas I worked and studied in for over 20 years was Bone Densitometry. This included scanning, undertaking many research projects and liaising with many clinical departments and the National Osteoporosis Society.

I am currently on the committee of your local Coeliac Society and have been asked to give a talk on DEXA scanning on the 27th April.

I will explain bone health and how bone mineral density is calculated to help with decision making for a treatment regime or monitoring conditions such as coeliac disease.

Due to the strict regulations I am unable to discuss individual cases, specific treatment regime or health issues.

Erica Dore

In the press





CLARE MARRIAGE, 65, founded Doves Farm Foods, an organic and gluten-free foods business, with her husband, Michael, in 1978. They live in Wiltshire and have three children, Jethro, 35, Rupert, 37, and Madeleine, 33. and

MY MOTHER was an amazing cook. I My Morner was an anazing cook. loved coming home from school to fresh, hot bread and her strawberry jam. I remember helping with everything, from shelling peas to making Christmas pudding.

But then Mum got very III and was advised to cut all gluten from her diet. At the time, gluten-free versions of anything just didn't exist. She lived off rice and malze-meal flatbread,

off rice and malze-meal flatbread, day in, day out. It was devastating. I started reading up on different cuisines that used Ingredients we could all eat, such as whole grains, beans, lentils, chickpeas and brown rice, but you still couldn't buy most of these in supermarkets – I had to go to special health food stores. We forget that, in the Sixtles and Seven-ties, it was almost impossible to get

hold of even wholemeal bread. Then I met my husband, Michael, a farmer. He was also interested in

organic food — a concept thought to be very strange back then. It went against the agrochemical farming that was in vogue, but we believed strongly that it was better for the

environment and for our health. We converted one strip of land on We converted one strip of land on our farm into an organic wheat crop, as an experiment. Two years later, it was flourishing, so we bought a grinding mill and made our first batch of organic, wholemeal flour. This was my lightbulb moment: using our maize crops, I realised I could make gluten-free flour for my mum. Suddeniv we were producing

mum. Suddenly we were producing food previously impossible to buy. We established Doves Farm Foods

on a budget of £1,000, initially making organic wholegrain and gluten-free flour. The early days were hard work; the supermarkets thought we were mad. Michael would climb a ladder mad. Michael would climb a ladder and pour grain in the mill and I'd pack it at the kitchen table. I had our first child four years in, and I remem-ber sitting up in the hospital bed the day after, doing the accounts. Today, we sell 47 types of flour and gluten-free foods such as breakfast cereals pastas and cookies Our

cereals, pastas and cookies. Our products are stocked online and in major retailers, including Tesco, Waltrose and Ocado. We've recently launched Freee By Doves Farm, home to all our gluten-free food produced in dedicated facilities. Our furnover lact year ways CB artistics turnover last year was £18 million. I won't forget the first time Mum,

now 89, tried our gluten-free flour — she was so touched and thrilled. And that's what it's all about. freee-foods.co.uk

BY FLORENCE SCORDOULIS



Event: Annual General Meeting Location: Rudgwick Village Hall, RH12 3JJ Date: Saturday 27th April 2019 Time: Arriving from 2pm, ready for 2:30pm start to meeting

Menu: Tea/Coffee (squash/juice for the children) and a selection of cakes

I/we would be delighted to attend. Please reserve spaces.

Name:....

Name:....

Payment and booking deadline

Cost: £3 per person. Please make sure your booking form and payment have been received by the local group by **Friday 12th April 2019**.

□ I have enclosed a cheque made out to **Coeliac UK - South Surrey** for £.....

 \Box I have paid through online banking, having transferred £..... to the local group bank account, sort code: **30-94-28** account number: **63221068**, ref **AGM 2019**

Confirmation of booking

□ Please confirm my booking and safe receipt of my payment by email at.....

 \Box Please confirm my booking and safe receipt of my payment by post. I have enclosed a stamped, self-addressed envelope.

Contact details

If you need to contact me regarding the event you can do so:

by email atby phone on

Other dietary requirements

If you or any of your party have additional dietary requirements (other than gluten free) please get in touch with the local group directly using the contact details below.

Completed booking forms

Please email your completed booking form to southsurrey@coeliac.org.uk

or post to: Alastair Buchan, 59 Fairlands Road, Fairlands, Guildford GU3 3HZ



Coeliac UK, 3rd Floor, Apollo Centre, Desborough Road, High Wycombe, Bucks, HP11 2QW T: 01494 437278 F: 01494 474349 www.coeliac.org.uk





Event: Fundraising Quiz & Supper Location: Merrow Methodist Church Hall Date: Saturday 18th May 2019 Time: 7.00pm

Menu: Jacket potato with a selection of fillings

I/we would be delighted to attend. Please reserve spaces.

Name:....

Name:....

Payment and booking deadline

Cost: £10 per person. Please make sure your booking form and payment have been received by the local group **by Friday 10th May 2019.**

□ I have enclosed a cheque made out to **Coeliac UK - South Surrey** for £.....

 \Box I have paid through online banking, having transferred £..... to the local group bank account, sort code: **30-94-28** account number: **63221068**, ref **Quiz**

Confirmation of booking

□ Please confirm my booking and safe receipt of my payment by email at.....

 \Box Please confirm my booking and safe receipt of my payment by post. I have enclosed a stamped, self-addressed envelope.

Contact details

If you need to contact me regarding the event you can do so:

by email atby phone on

Other dietary requirements

If you or any of your party have additional dietary requirements (other than gluten free) please get in touch with the local group directly using the contact details below.

Completed booking forms

Please email your completed booking form to **southsurrey@coeliac.org.uk**

or post to: Helen Searle, Flat 2 Milford House, Milford, Godalming, GU8 5HJ



Coeliac UK, 3rd Floor, Apollo Centre, Desborough Road, High Wycombe, Bucks, HP11 2QW T: 01494 437278 F: 01494 474349 www.coeliac.org.uk





Event: Children's Magic Lesson Location: Farncombe Youth Football Clubhouse, 97 Green Lane, Farncombe, Surrey, GU7 3RZ Date: Saturday 29th June 2019 Time: 3.00-4.30 pm Cost: £5 per child

Details

Suitable for ages 5-12 years old. Props for children to borrow during the lesson will be provided and a drink/snack will also be included.

Yes, my child would be delighted to attend. Please reserve for me spaces.

Child's Name.....

Adult's Name:.....

Payment and booking deadline

The event costs £5 per child. Please make sure your booking form and payment have been received by the local group **by Wednesday 29th May 2019**.

 \Box I have paid through online banking, having transferred £..... to the local group bank account, sort code: **30-94-28** account number: **63221068**, ref **Magic**

If you would like to pay by cheque, please email us at southsurrey@coeliac.org.uk to arrange.

Confirmation of booking

□ Please confirm my booking and safe receipt of my payment by email at.....

Contact details

If you need to contact me regarding the event you can do so:

□ by email at

□ by phone on

Other dietary requirements

If you or any of your party have additional dietary requirements (other than gluten free) please get in touch with the local group directly using the contact details below.

Completed booking forms

Please email your completed booking form to southsurrey@coeliac.org.uk



Coeliac UK, 3rd Floor, Apollo Centre, Desborough Road, High Wycombe, Bucks, HP11 2QW T: 01494 437278 F: 01494 474349 www.coeliac.org.uk





Event: Summer Barbecue Location: Clandon Regis Golf Club, Epsom Road, West Clandon, GU4 7TT Date: Saturday 10th August 2019 Time: 12.30pm, Food served from 1.00pm - 2.00pm

Menu: Burger in a Bun, Sausage, Chicken Kebab Selection of Salads Choice of desserts (lemon cheesecake, salted caramel torte or strawberries & cream)

I/we would be delighted to attend. Please reserve for me spaces.

Name:.....

Name:.....

Payment and booking deadline

The meal costs £22 per person including gratuity. Please make sure your booking form and payment have been received by the local group by Friday 2nd August 2019.

□ I have enclosed a cheque made out to **Coeliac UK - South Surrey** for £.....

 \Box I have paid through online banking, having transferred £..... to the local group bank account, sort code: **30-94-28** account number: **63221068**, ref **Barbecue**.

Confirmation of booking

□ Please confirm my booking and safe receipt of my payment by email at.....

 \Box Please confirm my booking and safe receipt of my payment by post. I have enclosed a stamped, self-addressed envelope.

Contact details

If you need to contact me regarding the event you can do so:

□ by email at □ by phone on

Other dietary requirements

If you or any of your party have additional dietary requirements (other than gluten free) please get in touch with the local group directly using the contact details below.

Completed booking forms

Please email your completed booking form to southsurrey@coeliac.org.uk or post to: **Mike Harrison, 3 Hitherwood, Cranleigh, Surrey, GU6 8BN**



Coeliac UK, 3rd Floor, Apollo Centre, Desborough Road, High Wycombe, Bucks, HP11 2QW T: 01494 437278 F: 01494 474349 www.coeliac.org.uk





Event: Family Picnic/Soapbox Race Location: Farnham Park then onto Castle Street, Farnham Date: Sunday 18th August 2019 Time: Midday Cost: Free of charge

Details

Meeting at midday in Farnham Park for a family picnic. Please bring your own food/drink. Then moving down to Castle Street, Farnham to watch the Soapbox Race 2019. We would love to see as many of you as possible to support and discuss living with Coeliac Disease.

Yes, we would be delighted to attend. Please reserve for me spaces.

Name:....

Confirmation of booking

□ Please confirm my booking by email at.....

Contact details

If you need to contact me regarding the event you can do so:

□ by email at

□ by phone on

Completed booking forms

Please email your completed booking form to southsurrey@coeliac.org.uk



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