

# NORTH SURREY LOCAL GROUP NEWSLETTER



North Surrey  
Local Group

Edition 6: October 2020

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## WELCOME FROM THE CHAIR

Well, days turned into weeks, weeks turned into months, and now we enter our third season with Coronavirus still impacting so majorly on our lives. We bring you this newsletter with sad hearts as we are still unable to host events or even begin to plan for when our coeliac community can once again join together for some tasty food, good chat and enjoyable company with whom we can swap recommendations and share experiences. The newsletter is a little thinner than usual as we have no events to celebrate or promote but, none the less, we hope you find it informative and, while reading it, please know we are still here to support you where we can. As always, we would love to hear from you with restaurant recommendations, recipes, reviews or experiences, or ideas for future events. If I could focus your attention to the questionnaire mentioned later in this edition, we really would appreciate it if you could give 2 minutes to provide us with some useful feedback for our committee to work with.

Finally, I would like to welcome the new members that have joined us during the year. Unfortunately, we have not been able to meet in person yet, but we look forward to having a chat with you at one of our events in the future. If you are newly diagnosed, you might find looking at past editions of the newsletter of some support, as we have regular articles sharing tips, advice and recommendations from our committee and our members. All past editions can be found at

<https://www.coeliac.org.uk/local-groups/north-surrey/newsletters/>

## Awareness and Fundraising

On the weekend of 19th – 20th September 2020, approximately 150 members of Coeliac UK helped complete the 2500km journey around the UK. Each member/family could take part by running, walking, rowing, cycling, skipping (and many other means) their target distance and then submitting their mileage to Coeliac UK to help meet the total distance of the challenge. It was great exercise and fun for those who took part, great publicity for Coeliac UK and a much-needed amount of money to support the funding of research and campaigns to help those living life gluten-free.

Coeliac UK, like many other charities, is suffering significant loss of financial income this year due to Covid, stating on their website:

*"Due to coronavirus, we're expecting to lose 75% of the income we normally receive through Challenge events this year – that's £80,000 - which is why we're reaching out to our gluten-free community for support."* (taken from <https://www.coeliac.org.uk/get-involved/fundraise-for-us/challenge-weekend/> on 30/09/20)

If you took part in the Challenge weekend or any other fundraising event for Coeliac UK, please do send us your stories and photos to share with your fellow North Surrey members in the newsletter.

## Upcoming 2020 Events

To use this quiet time more productively, we would like to get an idea of what activities and events appeal to our local group membership when we can meet again. For example, do you fancy picnics and events with no costs to pay upfront, or maybe you would like social events such as quiz nights, race nights, a social dance, party night or bingo? Are weekdays, school holidays, weekends, lunchtimes or evenings best for you? Does geography play a part in whether you participate? **If you could take a few minutes to complete the Monkey Survey questionnaire (click on the link) it would enable us to better plan for future events when we can start to meet up again. It is a short questionnaire (it will take approx. 2 minutes) and is anonymous. Thank you**

<https://www.surveymonkey.com/r/8SWYPZD>

## New digital resource to support you after diagnosis

Coeliac UK has launched a new resource to help support newly diagnosed members, especially in the current climate where it is proving more challenging to see a GP or dietician due to Covid restrictions.

There are a series of short videos on a variety of topics such as reading food labels, understanding what coeliac disease is and strategies for eating out. You can also speak with Nicola, one of the teams of Coeliac UK dieticians, who can help you through those first few days and weeks where everything seems new and daunting. For more information and access to the video visit <https://www.coeliac.org.uk/information-and-support/coronavirus-information-hub/new-digital-resource-to-support-you-after-diagnosis/>

## Mental Health and Wellbeing Resources

As many of you may still be shielding through this troubling time, it would be remiss of us to focus purely on gluten-free and coeliac disease when in fact it could be isolation, loneliness and sheer boredom that can be taking the most significant toll on people.

We are not the experts in this field, but for your reference, we would like to share some links to relevant websites and resources that have been created by the experts in the field of mental health and social wellbeing, should you feel that you may benefit from what they have to offer.

### World Health Organisation (WHO)

<https://www.who.int/docs/default-source/coronaviruse/mental-health-considerations.pdf>

<https://www.who.int/news-room/campaigns/connecting-the-world-to-combat-coronavirus/healthyathome/healthyathome---mental-health>

### Mental Health Foundation

<https://www.mentalhealth.org.uk/publications/looking-after-your-mental-health-during-coronavirus-outbreak>

### Coeliac UK

<https://www.coeliac.org.uk/information-and-support/coronavirus-information-hub/practical-support/>

### MIND – for better mental health

<https://www.mind.org.uk/information-support/coronavirus/>

### National Health Service (NHS)

[https://www.nhs.uk/oneyou/every-mind-matters/?WT.tsrc=Search&WT.mc\\_id=MentalHealthGeneric&gclid=Cj0KCQjws\\_r0BRCwARIsAMxfDRhGGhUq5GPv-sTXIVQb47PO0up92TM7zPOvJZY1DGM-uTWY6sYJd3QaAuBFEALw\\_wcB](https://www.nhs.uk/oneyou/every-mind-matters/?WT.tsrc=Search&WT.mc_id=MentalHealthGeneric&gclid=Cj0KCQjws_r0BRCwARIsAMxfDRhGGhUq5GPv-sTXIVQb47PO0up92TM7zPOvJZY1DGM-uTWY6sYJd3QaAuBFEALw_wcB)

## Prescriptions Update

In Edition 4, the 'Top Tips...' article discussed the postcode lottery for gluten-free on prescription. We have now received a response from the second Clinical Commissioning Group which serves in North Surrey and wishes to share with you the outcomes.

**NHS North West Surrey CCG** responded to my enquiry with:

*"Thank you for your enquiry regarding Gluten-Free on Prescription. All up to date information can be found on the Surrey Pad: <https://surreyccg.res-systems.net/PAD/Guidelines/Detail/4396> "*

**NHS South West London CCG** wrote to me as follows:

*"Dear Ms Cranefield,*

*I am writing to you in my position as Accountable Officer of the NHS South West London Clinical Commissioning Group (CCG). As you are aware, as of 1 April 2020, all South West London CCGs came together to form a new, single, CCG, known as NHS South West London CCG (SWL CCG). Accordingly, it is now SWL CCG that is responding to your complaint.*

*This response is in reply to your email of 28 April 2020, and my apologies for the delay in replying.*

*I note that you write on behalf of the North Surrey Local Group of Coeliac UK, and are requesting guidance on the availability, on prescription, of gluten-free products for people living in the area covered by the SWL CCG. I also acknowledge your comment that buying such products "over the counter" may be more difficult in these challenging times.*

*Unfortunately, it has not yet been possible to produce a South West London policy regarding this issue. This is due mainly to the impact upon the CCG's resources of the COVID-19 pandemic. I am sure you will appreciate the scale of this but, nevertheless, my apologies and an assurance that the absence of such a policy will be rectified as soon as circumstances allow.*

*In the meantime, the gluten-free products that South West London Boroughs allow to be prescribed (Wandsworth, Merton, Sutton, Kingston, Richmond but not, currently, Croydon) are those listed on page 944 of the National Drug Tariff: see link below.*

<https://www.nhsbsa.nhs.uk/sites/default/files/2020-04/Drug%20Tariff%20May%202020.pdf>

*However, I should add that, although such prescribing as above is allowed, most GPs no longer choose to prescribe these products as people are expected to buy them "over the counter." In light of this, I would hope, as the effects of COVID 19 begin to ease, this will be easier for your members and other similarly affected people.*

*I am sorry that I am not currently able to provide you with a more comprehensive response but hope that the information I have been able to include will be of some help.*

*However, if you are dissatisfied with any aspect of this response, please do not hesitate to contact the Customer Care Service at [contactus@swlondon.nhs.uk](mailto:contactus@swlondon.nhs.uk)*

*Thank you for your enquiry. The CCG considers any complaint or enquiry about the services it commissions as a vital part of reviewing and, where necessary, improving these."*

This latter response angered me greatly, and I forward it onto Coeliac UK to help build momentum in a campaign to change the situation so that the CCGs and indeed individual GP practices cannot just make up/bend the rules as they see fit or their budgets allow.

Coeliac UK fights tirelessly to help support the coeliac community by campaigning for CCGs to allow GF bread and flours to be ordered on prescription. But they need our help, and they need our voice to make the need real, to make it personal, to make it more than just about the bottom line.... a cost on a piece of paper....another budget cut. For ideas on how you can get involved, please visit....

<https://www.coeliac.org.uk/get-involved/campaign-with-us/fight-for-prescriptions/>

## Product Recommendation



### **Skinny Lager**

It is nice to find a reasonably priced gluten-free lager. I am not a great lager drinker and although I enjoy a nice GF Peroni or Daura Dam on a summer's day when socialising with friends and family or at the end of a tiring week, some brands can seem more expensive than regular lagers. I order it from Amazon, and it comes in a box of 12 for £14 (price correct in October 2020).

**Jon Cranefield**

## Top Tips for our newly diagnosed members (By Kirsty Cranefield)

I recently read an article which I found somewhat comforting, and I had to chuckle to myself as I know our family went through the exact scenarios, and I am sure it will ring true to so many of you. So perhaps less for information but more for reassurance that you are not alone in this, I wish to share our recommendations for educating relatives about the condition of coeliac disease – mainly grandparents!

Now, we are fortunate that right from day one when Jon was diagnosed in 2016 – both sets of our parents immediately researched and read up on all things coeliac so that they could support him through his transition to a gluten-free lifestyle. I think for an adult, it is slightly easier, as he could be independent in his choices, he was able to research, read labels and verbalise his concerns when eating out of the home. However, in 2017 when our daughter was diagnosed at the age of 5, it was harder as we were more concerned that she would not stop and say no to food being offered to her and that she would not have the confidence to question the food being offered to her, especially by relatives and close family friends.

The hardest problem with children diagnosed with the condition, is sometimes they don't understand themselves and much-loved traditions that they are used to sharing with grandparents (especially those revolving around food) can seem like a punishment if they are stopped. So, the trick in my opinion is to build your child's understanding of their own condition and encourage them to ask questions of everyone about the food they are being given. Encourage them to ask, "Is this gluten-free?" and if it's not, help them understand that it's not their fault – it's not anyone's fault and it is most certainly not a punishment.

Secondly, provide everyone that your child visits regularly with a stash of safe Gluten-Free treat foods and basic food items (bread, pasta) so that your child is never left wanting when everyone else around them is tucking into treats or a hearty meal.

Thirdly, if the child with coeliac disease has siblings or other close child age relatives, encourage relatives/close family friends to treat all the children the same by offering them all the same food rather than singling out the coeliac. Educate them about the good quality products that are naturally gluten-free and loved by all regardless. Sweets – Haribo/Maoam/Pez, chocolate – specific size Cadbury's bars or Bounty bars/Peanut M&Ms or Galaxy Minstrels, sausages/burgers – good quality meat products will be gluten-free (but teach relatives to check the labels), cake – you can't go wrong with the Betty Crocker Gluten Free cake mixes, crisps – Seabrooks have a good choice of flavours/M&S do interesting flavour sharing bags/many Kettle Chips flavours are GF and some are available in both sharing and individual size bags.....

When you are with your child, it's easier to oversee everything being given to them and eaten around them but, trusting others with your little one is a completely different kettle of fish, and I can tell you I was one 'anxious mummy' when my two had their first sleepover at Grandma's post my daughter's diagnosis. I went

through every meal with my mum, right down to drinks on offer, sauces on the table, where to cook things and how to dish up. My poor mum must have felt like I thought she was a complete imbecile and it was a real “teaching Granny to suck eggs” situation as sleepovers were not a new thing, it had been done time and time again. However, I think we both felt better for going over everything because then my mum could be more relaxed and enjoy her time with her grandchildren and she knew everything she was offering was safe for the both of them. I did have sympathy for my dad though, as he LOVES his food and my mum spent the entire weekend telling him what he could not have while the kids were there and to mind where he was dropping his crumbs! But do you know what, the next sleepover was easier and more relaxed for everyone and it all became ‘normal’ to think gluten-free. And most importantly, the kids got their precious time with their Grandma and Grumpy, and then their Granny and Pop Pops, something they look forward to and cherish, with lots of food, treats and smiles – which after all – is what time with Grandparents is all about!!

I have a smile on my face as I type this, as I know both sets of grandparents will eventually be reading this article as they all became members of Coeliac UK and our local group in order to learn, support, raise funds and create greater awareness of this condition. Perhaps that is the final message – if your family and friends are willing, take them on the journey with you. You can learn together, try out new things together and share the highs and lows together – their support is what makes the transition to a gluten-free lifestyle easier for the coeliac.

For the full article, I read visit: <https://www.allergicliving.com/2018/05/02/when-grandparents-dont-get-gluten-free-4-steps-to-educating-about-celiac-disease/> which I read on 20/04/20

When Grandparents Don't Get Gluten-Free: 4 Steps to Educating About Celiac Disease

By: Alice Bast

### **Recipes (Please check individual links for nutrition information)**

For those of you who have not yet ventured onto the Doves Farm website, they have a great range of Gluten-Free recipes that use their products. You can filter the search

<https://www.dovesfarm.co.uk/recipes/freee>

Just this week, I decided to cook an old favourite my mum used to make when I was a child, but obviously had to adapt it to be GF. Now I am not a great cook, I am not confident at baking, my cakes do not always work, I can follow a recipe to a T and it turns out differently every time and I have never ever made my own Yorkshire Puddings before – I am a frozen, heat in 4 minutes Yorkshire Pud kind of girl! So, to brave a ‘Toad in the hole’ (or as my son rather hilariously referred to it afterwards “that Frog in a bog was yum!”) was a bold move for me.

I knew just adapting my mum's original recipe to swap in GF flour was a risk, as not all things adapt that easily and still turn ours as well. So, I looked up online and found the Doves Farm version which worked a treat – even for me! I would go as far as to say its ‘foolproof’ if I could manage it and have 4 clean plates at the end of dinner with everyone asking for more. So, voila... please see the link below to the full recipe

<https://www.dovesfarm.co.uk/recipes/toad-in-the-hole>

Enjoy!

If you try out any of the other recipes from the Doves Farm website, please do send in a review and maybe even a photo, to share with your fellow members.