

Editor's Message

Spring has sprung (thank goodness)! Alongside the changing of the clocks and the seasons, spring brings with it great change amongst our local groups as we say goodbye to retiring committee members and welcome all new volunteers to the local groups. Thank you to all for your commitment to the charity, members and those living gluten free.

For those new to volunteering, our Volunteers' Update provides a reminder of **upcoming events** as well as showcasing what **local groups have been getting up to in their areas** (Events). You can read about activities and developments within the charity and learn more about how you and your **local group can support or get involved** (News and opportunities). Each update also including information about **the running of your local group** (Governance) and **contact details of the Volunteering team** should you have any questions or need further information (Contact the team). Finally, we provide an update on all newly **accredited venues** (Recently accredited) for you to pass onto members.

Happy reading! Miranda

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Ethe gluten freeVolution =

Awareness Week 2017, 8-14 May Join our Gluten Freevolution!

Awareness Week this year will see the launch of our Gluten Freevolution. This year's campaign is all about food. We will be working to improve the availability of gluten free food:

- when travelling eg at motorway services and train stations
- in hospitals
- in the "ready to eat" section at supermarkets and
- in takeaway restaurants.

To support our campaign we are asking our local groups to:

- host a take away dinner and quiz night
- organise a meal out
- hand out leaflets
- add five new venues to the Coeliac UK venue guide
- leave feedback at supermarkets
- support our campaign on social media.

We are asking local groups to raise a combined total of £500 for Coeliac UK as part of this year's campaign. The local groups that raise the most will be rewarded with a new pop up for their local group.

The Gluten Freevolution will take place throughout 2017 so even if you don't have anything organised just yet there's still plenty of time to get involved.

Campaign packs will automatically be sent to all local groups in the next few weeks. If you would like a copy of our quiz, collection boxes or require any further information please don't hesitate to get in touch. We wish you every success with your upcoming events and activities.

York food fair cancelled

It is with great sadness that we have to announce that the 2017 York food fair, due to take place at York college on 13 May, has been cancelled. We send our thanks to the Hull and East Riding Local Group who have successfully organised and hosted this event for the past 15 years. We know that they are very disappointed not to be able to hold an event this year but unfortunately they've had no option but to cancel following low booking numbers amongst manufacturers.

Volunteers' Conference booking form

We are delighted to be returning to etcVenues in Birmingham (home of the 2012 Volunteers' Conference and now a Coeliac UK accredited venue) for this year's event.

The venue will be open from 9am where you can join us for a gluten free breakfast before the day's talks start at 10:30am. A two course sit down gluten free lunch will be provided to all and the conference will end at 4pm.

As always, the conference offers a fantastic chance to meet with other volunteers and staff, learn about what's happening within the Charity, share information, learn and problem solve.

The agenda is still being set so if there is anything specific you would like to see addressed please let us know by emailing volunteering@coeliac.org.uk. You can reserve your place by emailing volunteering@coeliac.org.uk - booking forms to sign up to the different workshops will be sent out in June.

June food festival reminder

Your exclusive invitation to Coeliac UK's Gluten free food festival AJ Bell Stadium, Salford, 24 June 2017

Quite simply, our volunteers are the backbone of all that we do here at Coeliac UK. As a thank you for your ongoing support, we are sending you a personal invitation to our Gluten free food festival which gives you exclusive access to the festival between 10-11am so you can have time to explore and talk to manufacturers and us ahead of the crowds.

We'll be celebrating all things gluten free with over 40 producers and

manufacturers offering glorious gluten free products for you to sample and buy. And what's more, the day will also give you:

- a VIP area where you can meet the Coeliac UK team
- a free dietetic clinic giving you the chance to book a face to face meet with a registered dietitian
- specialist talks led by leading Gastroenterologist Professor David Sanders
- cookery demos hosted by Coeliac UK's Home Economist
- and special guest feature to be announced.

Register <u>now</u> and enter the promotional code **Volunteer** for your exclusive entry ticket and to claim your free goodie bag at the end of the festival.

Find out more about the day's events and the up to date exhibitor listing at www.coeliac.org.uk/foodfestival or give us a call on 0333 332 2033.

We look forward to seeing you there!

Out and about with local groups

To find out what our local groups have been up to so far this year please visit our webpages.

Upcoming food fairs

- 22 April 2017 Bristol food fair
- 29 April 2017 Bournemouth & Poole food fair
- 3 June 2017 Lincolnshire food fair
- 10 June 2017 South Wilts food fair
- 17 June 2017 Birmingham food fair
- 16 September 2017 Gloucestershire food fair
- 23 September 2017 Beds and Mid Herts food fair
- 7 October 2017 Wessex food fair
- 8 October 2017 Cumbria food fair
- 28 October 2017 Cardiff food fair
- 11 November 2017 Hereford food fair
- 26 November 2017 Bath food fair

Please visit our website for timings and addresses for food fairs.

Volunteers' Conference 2017

The Volunteers' Conference for 2017 is on Saturday 14 October 2017 in Birmingham.



Branding webinars and documents

Thank you to everyone who took part in our branding webinars at the start of the month. The sessions introduced the new brand, individual local group logos and associated merchandise.

Getting your new logo: Over the coming month all local groups will be sent their new logo and both an electronic and hard copy of the brand guidelines.

Active on social media? If you are active on social media let us know and we will send on the relevant logos to update your pages.

Updating the local group communication pages: We are currently arranging for the local group communication pages to be updated with our new colours and fonts. Once that has been done the Volunteering team will start uploading your new local group logo to your pages.

Replacing merchandise

To ensure a professional, consistent look for people to engage with we require all local groups to update their merchandise with our new brand by the end of 2017.

We will be working with local groups to help get this done, but to do so we need to know:

- what merchandise (pop ups, banners, tshirts...) you have and
- when you ordered them.

Please complete this <u>short survey</u> and we will then liaise with you on an individual basis to ensure your items are up to date.

Local group business cards

Our new local group business cards will be with us in the next few weeks. The back of the cards have been left blank for you to add your own information. To order up to 200 cards for your local group please contact volunteering@coeliac.org.uk

Electronic letterhead

We are also in the process of developing a personalised electronic letterhead for each local group. A copy of this will be sent out automatically to the Group Organiser and Group Secretary once completed. If you have a mailing coming up that you need the letterhead for let us know and we will put you at the top of the list!

Lloyds update

It has been a long, bumpy road but we are delighted that 57 local group bank accounts have now been finalised with signatories in place and online banking activated.

Bank statements: We can provide a bank statement to all those local groups still awaiting online access. To obtain such please email volunteering@coeliac.org.uk and we will email a copy to you within two working days.

CAF charges: As we have reported in the past, unfortunately with interest rates still low, banks do have the right to implement charges on accounts. We are, of course, incredibly disappointed in CAF's decision to do this. Once your Lloyds account has been finalised you will be sent instructions on how to close your CAF bank account.

Closure of Cambridgeshire Local Group

Unfortunately, in light of recruitment issues, the Cambridgeshire Local Group closed at their AGM last month. We extend our thanks to Ayshea Bliss and her committee for the many years they gave to the Charity and members.



Gluten free prescribing – in the news

Gluten free prescribing has once again been in the headlines following a breaking story last month. In an interview to the *Daily Mail*, Chief Executive of NHS England, Simon Stevens, announced he was looking at the removal of gluten free foods on prescription.

We are deeply disappointed by this announcement. At Coeliac UK we know that gluten free prescribing protects vulnerable patients. As stated by Sarah Sleet, Chief Executive, "I am very concerned that vulnerable and elderly patients today will be waking up to the headlines that prescriptions for the breads and flours that they rely upon as part of a healthy balanced diet will be removed in one fell swoop. The worry and distress this will cause should not be underestimated.

Although Mr Stevens goes on to talk about a consultation on the proposals the clear impression is that this is a done deal.

"Furthermore the comments he makes about availability of such products, for example in Lidl, show the lack of understanding about the reality of access. In fact Lidl for example do not routinely stock such products. Research shows that budget and convenience stores, which are relied upon by the most vulnerable such as the elderly, those with disabilities and on low incomes, have virtually no provision."

Mr Stevens also misleadingly implies that significant sums are spent by the NHS on biscuits and cakes. He will know that guidance, backed by Coeliac UK, for many years has rejected such spend.

It is also stated that 'the price of gluten free alternatives has come down substantially'. This is not backed up by the evidence. Industry data since 2008 demonstrates that the cost difference between gluten free breads and flours is six times and has not gone down throughout that period.

Gluten free prescribing – what can be done What we are doing

A public consultation was launched by the NHS on Friday 31 March. Since then, Coeliac UK have been liaising with our stakeholders (eg the BDA and BSG) before we respond comprehensively to the consultation. We are looking forward to the opportunity to engage with the NHS in the consultation process, having already written to Simon Stevens, to request a meeting to make sure that the needs of patients with coeliac disease are realised and that an equitable solution is found.

The official announcement today sets out three options as part of the consultation:

- option 1- make no changes: Make no changes to the National Health Service
- option 2- end prescribing of gluten free foods in primary care
- option 3- restrict prescribing of gluten free foods: to only allow the prescribing of certain gluten free foods (eg bread and flour) in primary care.

The deadline to respond is 22 June which gives us time to make our case again.

We will be trying to persuade the NHS to consider alternatives that will deliver cost savings, while providing support for patients with coeliac disease and particularly the most vulnerable, to support dietary adherence and reduce the risk of long term complications which could cost the NHS more in the long run.

What you can do - Share your story with Coeliac UK

It is incredibly important that we balance the statistical evidence with real life stories. We are in need of stories from people who:

- use prescriptions regularly and can tell us what cuts will mean to them
- are living in an area already experiencing cuts who can tell us what impact prescription restrictions are having
- relied on prescriptions on when first diagnosed to help them adjust to the diet

If you are willing to share your story please complete this form

If you have a meeting coming up where you would be able to hand out story forms to members, again let us know and we will send out forms and addressed Freepost envelopes.

What you can do - Early Day Motion

MP Keven Jones has put forward an Early Day Motion in support of gluten free prescribing. We are asking everybody to contact their MP and ask them to support the Motion.

To find your MPs details go to www.theyworkforyou.com
To find out more about the Early Day Motion go
to www.parliament.uk/edm/2016-17/1123





Browns Brasserie & Bar

Browns Brasserie & Bar, have successfully achieved gluten free accreditation at all 25 of their locations throughout the UK alongside the launch of their all new gluten free menu. From Brighton to Edinburgh, you're bound to find a restaurant nearby offering a wide selection of their traditional all day brasserie dishes.

www.browns-restaurants.co.uk



Chiquito Restaurant Bar and Mexican Grill

Chiquito Restaurant Bar and Mexican Grill have gained GF accreditation alongside their all new gluten free menu. 88 restaurants across the UK now offer an extensive range of gluten free options so you're bound to find a gluten free Tex-Mex somewhere near you!

www.chiquito.co.uk/menus/gluten-free



One Aldwych

A relaxed and informal restaurant in London's definitive contemporary hotel, newly GF accredited One Aldwych, Indigo offers a creative British menu, which is entirely gluten and dairy-free. Crafted by Executive Chef Dominic Teague, the menu incorporates the finest seasonal ingredients carefully sourced from the British Isles.

www.onealdwych.com/food-drink/indigo



Bocconcini Bakery

Bocconcini Bakery are a gluten free bakery based in North West London. Using gluten free flours imported from Italy, Bocconcini Bakery provide great tasting, traditional pizza, ciabatta, focaccia, rosetta and baguettes. All of Bocconcini Bakery's recipes are gluten free and they have recently gained GF accreditation.

www.bocconcinibakery.com



We'd love to hear from you!

volunteering@coeliac.org.uk / 01494 796118

Volunteering team

The best way to contact the Volunteering team is by emailing volunteering@coeliac.org.uk as this email address is monitored and cleared daily whereas personal email addresses are not.

Miranda Brooks, Head of Volunteer Development

9am – 4.30pm - Tuesday, Wednesday, Friday

Telephone number: 01494 796118

Coralie Meade, Volunteers' Assistant

8.30 – 4.30pm - Wednesday to Friday Telephone number: 01494 418361

Bharpur Gill, Volunteers' Assistant

9am – 5pm, Monday to Friday Telephone number: 01494 796117

Isobel Ford, Volunteer Coordinator

9am – 5pm, Monday to Friday Telephone number: 01494 796720







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