



Volunteers' Update

February 2016

Welcome to this edition of the Volunteers' Update which has a slightly different look and feel, please see the news and updates section to see why.

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Events food fairs

Upcoming food fairs

5 March 2016 - Wirral food fair

10am-2pm

Ellesmere Port Civic Hall

Civic Way

Ellesmere Port

CH65 0AZ

12 March 2016 - Leeds food fair

2pm-4pm

Pudsey Civic Hall

Dawson's Corner

Leeds
LS28 5TA

23 April 2016 - Bournemouth and Poole food fair

1pm-4pm
Parkstone Grammar School
Sopers Lane
Poole
BH17 7EP

14 May 2016 - York food fair

10.30am-2.30pm
York College
Sim Balk Lane
York
YO23 2BB

21 May 2016 - Liverpool food fair

11am-2pm
Old Police Station
Lark Lane,
Liverpool
L17 8UU

18 June 2016 - Lincolnshire food fair

(time tbc)

The Venue
Grantham Road
Navenby
Lincolnshire
LN5 0JJ

2 July 2016 - Coeliac UK Annual Conference and food fair

Timing TBC
Bath Racecourse
Lansdown
Bath
BA1 9BU

8 October 2016 - Penrith food fair

10.30-2.30
Penrith Leisure Centre
Southend Road
Penrith
CA11 8JH

15 October 2016 - Hereford food fair

11am-2pm
Hereford Leisure Centre
Holmer Road

Hereford
HR4 9UD

22 October 2016 - West Sussex food fair

10.30am-14.30pm

The King's Centre

33-35 Victoria Road

Burgess Hill

RH15 9LR



Volunteers' Update – the stats!

The October 2015 Volunteers' Update was:

- sent to 518 Committee Members
- 295 people opened the update (56.9%)
- 56 people clicked on links (10.8%)
- The top links clicked were (by a long way) the Local Group Survey results

The December 2015 Volunteers' Update was:

- sent to 520 Committee Members
- 262 people opened the update (50.6%)
- 32 people clicked on links (6.2%)
- The top links clicked were Local Group Guidance and Food Fair Guidance

Whilst this tells us that over half of the Local Group Committee Members opened it, it doesn't tell us whether somebody from **every** Local Group read it or whether the information was shared with other Committee Members who maybe didn't.

As the Update often contains important Governance related information it is essential that all Local Group Committees receive and share that part of it. Therefore in this issue the essential information that you need to support you in running your Local Group will be listed briefly in the Update, it will appear in full on the webpages and will be followed up with an email sent direct to Group Organisers.

We will be focusing the main part of the Volunteers' Update around news and information from Coeliac UK Teams and other Local Groups. As usual we would welcome your feedback, so please let us know how this works for you.

AGMs

It's that time of year again when you'll be starting to hold your AGMs or putting a date in the

diary for your AGM so this is a timely reminder to please provide your updated Committee Member details by completing the contact information [form](#) and returning it to either Barbara or Coralie.

Bank accounts

You can keep up to date with the Local Group bank changes by checking out our dedicated news [page](#).

Crossed Grain magazine deadline

The deadline for summer Crossed Grain is Thursday 3 March (by noon at the latest), please make sure you don't miss this deadline if you'd like something included in the magazine.

If you'd like to submit an event to be included, please ensure you include events from 7 May to around 15 October as distribution for the winter issue will start on 10 October.

Cumbria floods

Jean Foster, Group Organiser of the North, East and West Cumbria Local Group, has completed some fantastic work throughout the ravaged area of Cumbria. Despite bridges disappearing, roads remaining flooded and general chaos, Jean and her husband Peter have been visiting Members with bread, Christmas cakes, biscuits and mixed boxes of food as well as delivering boxes of gluten-free goodies to food bank centres across the county. A truly magnificent feat I'm sure you'll agree.

Food fair guidance

If you're thinking of running a food fair or you've already got one planned then why not check out our food fair guidance document which has been reviewed and [updated](#).

With more new businesses starting up and coming to exhibit at food fairs, we thought it would be useful to give you some more information on the law on [labelling](#) and what manufacturers should be doing.

Ensuring gluten-free producers at food fairs are complying with the law

As the market for gluten-free foods continues to expand, more and more businesses are producing gluten-free foods and many of you organising food fairs around the country are seeing increasing numbers of local businesses popping up producing great gluten-free offerings. With more new businesses starting up and coming to exhibit at food fairs, we wanted to give you a little refresh about the law and what manufacturers should be doing.

Gluten-free

The law on gluten-free was published in January 2012, and controls the use of the labelling term gluten-free. The introduction of the law means gluten-free can only be used to describe food which contain 20 parts per million (ppm) or less of gluten. Whilst the law specifies the allowable levels of gluten in products labelled gluten-free, it doesn't specify how manufacturers and caterers achieve this, however guidance is available from the [Food Standards Agency](#).

Using the right ingredients is the first thing to consider to make sure that only gluten-free ingredients are being used. This is particularly important for high risk ingredients like flours. Businesses need to ensure that they have controls in place to make sure that ingredients are

not contaminated during all stages of production, from managing incoming ingredients and storing them to preparation, cleaning and packaging.

To exhibit at a food fair, products being sold or sampled must be gluten-free. Businesses wishing to exhibit at food fairs must make sure that they have processes in place to make sure the final products are gluten-free. Carrying out some analysis of gluten levels in final products is a good way to check that the processes in place are effective.

Allergen information

Legislation brought in at the end of 2014 requires manufacturers and caterers to provide information on the allergens in the foods and/or meals served. Businesses exhibiting at food fairs must meet these requirements. For packaged foods, manufacturers must emphasise all allergens in the ingredients list. For foods sold loose, for example meals served by caterers and pies and pasties sold unpackaged, the business must be able to provide information on any ingredients that contain any of the 14 allergens.

Further information

Information on the requirements for exhibitors can be found in the Food Fair Guidance.

Information for manufacturers can be found here: <https://www.coeliac.org.uk/food-industry-professionals/gluten-free-and-the-law/manufacturing-and-the-law/>.

Information for caterers can be found here: <https://www.coeliac.org.uk/food-industry-professionals/gluten-free-and-the-law/catering-and-the-law/>.

For any queries about labelling, you can contact the Food Policy team via: <https://www.coeliac.org.uk/form/food-policy-and-legislation/>.

New parent child support group

With the brilliant support of the Swansea Local Group, Member Shelly Evans has set up a fantastic parent child support group at a playcentre in Port Talbot for local parents whose children have coeliac disease. This has provided a unique opportunity for parents to network, support one another and share experiences in an informal setting while their children enjoy supervised play.

The first event took place on Tuesday 26 January and twelve parents and children attended the event. This will now be a regular event taking place on the last Tuesday of every month. Fantastic work by Shelly setting this up and it is great to see Graham and the Local Group supporting her in this new venture.

The launch of Gluten-free Under Thirties (GUTs)

Saturday 23 January saw the first official event of the new Coeliac UK GUTs - Gluten-free Under Thirties Group at the University of Leicester. The day brought together 20 Members aged 18 to 30 from across the UK to network, hear about research and campaigns, and elect the new GUTs Committee.

Well done to Fearon on organising an excellent event. It would be fantastic if you could promote GUTs to your Members aged between 18 to 30 and help GUTs engage with as many people as possible via their Facebook page. [Join their Facebook Group](#) or [email their committee](#) for more information.

Fundraising

Fancy taking on a challenge? [Visit our website](#) to browse the challenges we have this year.

Out and about with Local Groups

Buckinghamshire Local Group



A group of thirty seven from the Bucks Local Group celebrated Christmas by gathering together at Aylesbury College in their William Harding restaurant named after a local benefactor, who left his personal estate and land as endowments to a charity from which the College has benefitted. As the college runs a comprehensive catering course we were able to put the students to the test under the supervision of their chef/lecturer. We are helping the students by widening their culinary experience and the students are helping people with coeliac disease by providing a restaurant quality meal that is completely gluten-free. Our menu consisted of a good choice of three starters, four main course and four desserts followed by tea or coffee and mince pies.

Everyone enjoyed the evening and felt the friendly students had done their best especially as some of them were in the first term of their course. All in all a very enjoyable evening for everyone concerned.

Glasgow Local Group



The children's Christmas party was well attended this year with more children attending than previous years. The entertainment went down well with the magician's tricks even better and Santa was well received by the children who loved their gifts but loved the food even more. They enjoyed not having to check if the food was gluten-free and can't wait for the next Christmas party.

Manchester Local Group



The Manchester Local Group enjoyed a great New Year three course gluten-free meal at Nick's Restaurant in Westhoughton, Bolton on Friday 8 January 2016. The occasion was very enjoyable and the food was excellent. Thank you to Nick's for a great evening.

South Hertfordshire Local Group



51 of the South Hertfordshire Group Members and partners enjoyed a splendid three course gluten-free Christmas meal at the Restaurant in the West Hertfordshire College in Watford provided by the trainee chefs and waiting staff. These meals provide superb value for our Local Group and excellent practice in catering for coeliac customers for the catering students.

[The Allergy & Free From Show is heading to Scotland - attend for free](#)

2016 will see the launch of the long awaited Allergy & Free From Show Scotland sponsored by Genius Gluten Free. This new event takes place in the SECC, Glasgow on Saturday 19 and Sunday 20 March and Coeliac UK Members, their family and friends, can attend for free.

Find a hall packed with gluten-free products to try and buy, health talks, Free From cooking classes, a chance to meet and chat to the Coeliac UK team, and obtain advice from the UK's top dietitians.

[Claim unlimited free tickets.](#)

[Cardiff update](#)

It's great to hear that we will soon have an active Committee working in the area again. Many thanks to those who have taken on roles and shown commitment to making it a success (and to Tristan for hosting the meetings).

Scotland update

We're looking for volunteers in Scotland willing to offer some of their time to give talks and presentations on coeliac disease, the gluten-free diet, and the work of Coeliac UK.

We're often approached by clubs, societies and workplaces to give talks on coeliac disease and it's a great opportunity to raise the profile of the condition and the Charity, and to spread our campaign message on diagnosis, signs and symptoms.

For this role, we're looking for volunteers with previous experience of public speaking or giving talks or presentations.

If you'd like to register your interest or want to find out more, please contact Myles Fitt, Scotland Lead at myles.fitt@coeliac.org.uk

Get involved in NCVO's photo competition

The National Council for Voluntary Organisations (NCVO) has launched a photo competition to celebrate the work of the voluntary sector.

The NCVO is keen to see your photos within the theme of 'connections' and we're asking you to showcase images that you feel demonstrate the link you have with us and other volunteers.

"Whatever form of connection your organisation creates, we would like to see it – whether it's the connections that charities create between people, the connection that people have to their personal causes or the work they do that connects communities" – said NCVO.

So whether you have a great photo from a recent food fair, an evening out with your Local Group or a fundraising photo – get your thinking caps on and enter your photos into the competition. Not only could you have your photos displayed for all to see and the chance to win £250 print credit, you could help us spread awareness of Coeliac UK and the work we do for those with coeliac disease.

The competition is open until 18 March. [Enter your photos now.](#)

Local Group webpages

As you know we're updating and expanding the information and guidance available to Local Groups on the website, and alongside that we have been looking at the set up of Local Group pages. One area that seems to cause some confusion is the map headed '**Local venues**'. This map shows the gluten-free accredited venues, and no gluten-containing ingredients accredited venues and standard listings that have been recommended by our Members or the venue directly. The GfG (Gluten-free Guarantee) approved pin is used to show supermarkets that have signed up to the GfG. Some people visiting the pages however assume that these are venues where the Local Group meets etc. as the heading really isn't clear. Could all Local Groups please make an amendment using the following text, or something similar, to explain the purpose of the map:

This is a map of GF (gluten-free) accredited venues, and NGCI (no gluten-containing ingredients) accredited venues and standard listings which have been recommended by our Members or the venue directly. The GfG (Gluten-free Guarantee) approved pin is used to show supermarkets that have signed up to the GfG.

Useful resources

Further to the recent changes we've made to the webpages we've now added a '[Useful Resources](#)' page which we hope you'll find useful. The page is split into two sections, **Volunteer Support, Training and Management** and **Welfare and Advice** and provides links to other organisations and a short explanation of what the organisations do. The first section provides details of organisations that may be able to help in the running of your Group by providing guidance, support or training etc. The second section provides details of organisations that you may need to signpost some of your Members to if they need more support and help than the Local Group can provide.

Please remember that you can always refer your Members to our Helpline: 0333 332 2033

Update from Sue

Hello everyone,

Despite a long Christmas and New Year break it feels like it's been a really busy time since the last Volunteers' Update.

The Volunteering Team have been reviewing some of our guidance for volunteers (including organising food fairs etc), carried out a review of our webpages and been involved in discussions about the changes to Local Group banking. We are reviewing how we deliver the Member2Member programme, launching a new Health Campaigner role (37 volunteers so far), piloting two other roles to be launched asap and we now have 150 people in our Campaign Network (join now if you haven't already done so!).

We attended the GUTs AGM / launch in Leicester on 23 January and were really happy to meet a new Committee of young people who are all passionate about furthering the objectives of Coeliac UK and meeting and supporting people through their Facebook page. A massive thank you to Fearon and her colleagues for organising a great day.

So thanks to everyone for giving your time to help make these things happen and to all our Local Groups for delivering a fantastic range of local events bringing people together throughout the Christmas period - with a very special thank you to Jean Foster (see full piece later in the Update).

We are now racing towards (if you haven't already had them!) Local Group AGMs, food fairs and Awareness Week. Last year Local Groups did a fantastic job of raising awareness of the '**is it coeliac disease?**' Campaign so if you have any fresh ideas for how Local Groups and individuals can get involved please let us know and we will put them up on the webpages.

I hope you find the Volunteers' Update interesting and hopefully inspiring, we are always keen to receive your feedback.

Hang on everyone, it'll soon be spring!

Sue



We're keeping the momentum of our *Is it coeliac disease?* campaign going for this year's Awareness Week and as ever, we need your help! From 9 - 15 May 2016, we'll be focusing our efforts on highlighting the most commonly reported symptoms of the condition and prompting people experiencing symptoms to ask themselves, 'Is it coeliac disease?'

How you can help

- **Join us as we take part in our national Coeliac UK Leafleting Day**
 On Saturday 14 May we'll be hitting the streets of towns up and down the UK to make a big impact across the country. You can make a difference by becoming an organiser for your local National Leafleting Day and coordinating your local effort. This could be handing out leaflets on your local high street, at your pharmacy, supermarket, school - anywhere with a large volume of people. We'll have more information soon and you can sign up to become an organiser of a leafleting event.
- **Help us flood social media**
 Support Awareness Week from the comfort of your own sofa. Support our Thunderclap campaign, which includes our key Awareness Week message written as a social media status, to share with all your friends and followers. All you need to do is visit our Thunderclap page when it is available and pledge your support, then during Awareness Week, our status will be sent out from the accounts of everyone who has pledged their support so that their friends and followers can see it too. It's that simple!
- **Grab your camera and take a selfie**
 Get thinking about how you could explain one of your symptoms of coeliac disease with a photo. We're looking to put you at the heart of the campaign, so what better way to explain one of your symptoms than to take a photo of yourself? We've produced some selfie frames which will be available soon – look out for more details on our website and on social media.

Look out for our Awareness Week campaign toolkits which will be available soon, and will contain lots more information on how you can get involved and support the cause this Awareness Week.



Policy, campaigns and research

Gluten-free prescribing: the good, the bad and the ugly

2016 starts with further cuts to gluten-free prescribing in Suffolk

NHS Ipswich and East Suffolk Clinical Commissioning Group (CCG) has implemented a new policy to restrict the prescribing of gluten-free food for patients with coeliac disease and DH. The change cuts the service for all but those aged 19 years or younger who will continue to receive eight units a month of bread, pasta, flour and bread mixes. The new policy took effect on 15 January 2016.

From 1 February, patients in the NHS West Suffolk CCG area will also have their NHS gluten-free food prescribing service cut, again with the exception of those aged 19 years or younger, who will be able to receive up to eight units per month of bread, pasta, flour and bread mixes.

Coeliac UK has continued to stress the importance of prescriptions to support the adherence to the gluten-free diet, the benefits of contact with the health service and the pressing concerns of the costs and availability of gluten-free food, particularly for the most vulnerable patients, but on this occasion we've been unable to persuade the two CCGs to retain their service for adults.

[Further information on these changes.](#)

Better news in the Vale of York

For those living in the NHS Vale of York CCG, the news is much better. The NHS in the Vale of York CCG is demonstrating a willingness to innovate to find a long-term solution to NHS funding pressures. The CCG has announced a trial of gluten-free food vouchers involving 100 participants due to begin on 1 February.

The gluten-free food vouchers will be redeemable in local M&S, Co-op and Morrisons stores, as well as Tullivers health food shop in York. It is hoped that the voucher scheme will both improve the service to patients and free resources for the NHS. Find out more about the scheme [here](#).

The scheme is a great example of what can, and should, be done before there is any consultation to cut or restrict gluten-free food services to patients with coeliac disease or DH.

Mid Essex update

Finally, Coeliac UK has also recently attended a meeting of the Essex County Council's Health Oversight & Scrutiny Committee (HOSC) to make the case for retaining prescribing services in the NHS Mid Essex CCG area.

The Mid Essex CCG consulted late last year on proposals to cut services and presented their findings to the HOSC in January. Coeliac UK Members have responded in both strength and

numbers, with the CCG receiving more than 400 submissions opposing the cuts and six of our Members also attended the HOSC meeting. You can watch a full video of the meeting online [here](#).

Concluding the meeting, Essex Councillors were unable to either endorse or reject the CCGs proposals, based on a lack of detail on the wider CCG budget issues and constraints, and local health needs and service requirements, but were able to ask probing questions of the CCG, including an exploration of alternative options and the consultation process.

On 28 January, Mid Essex Clinical Commissioning Group (CCG) made the decision to stop the prescribing of gluten-free foods with immediate effect. This decision was made despite Coeliac UK making a strong case for keeping gluten-free prescriptions over the last few months. Further information is available on [our website](#).

Campaign Network

The Coeliac UK Campaign Network is our Group of Members and supporters who are passionate about campaigning to improve the lives of those with coeliac disease. The Network was relaunched last year and now have around 150 Members signed up who have been involved in some excellent campaigning locally across the UK.

We know many of you campaign within your Local Groups and may be interested in joining the Campaign Network to keep updated with campaigns, get involved in activities and have the opportunity to connect online with fellow campaigners. [Sign up now](#) to join the Campaign Network or email us at campaigns@coeliac.org.uk. The only requirement is an email address and a willingness to add your voice to our campaigns.

Feeling inspired? Read more on Eileen's work on our [website](#).

[Let us know what campaigning you are doing in your local area.](#)

Local Group networking

Thank you to Committee Members who have been in contact to express their interest in networking with Local Groups close to them. It's fantastic to see you collaborating with neighbouring Local Groups to share ideas and best practice, and we're looking forward to seeing what comes out of it.


If you'd like any help in setting up a network meeting with other Local Groups near you or if there is anything we can do to support you don't hesitate to get in touch by emailing Izzy at Isobel.ford@coeliac.org.uk. We'd love to keep updated with how collaboration between Local Groups progress so please keep us in the loop with any networking meetings or joint events.



Contact the team

We'd love to hear from you!

volunteering@coeliac.org.uk 01494 796118

 Coeliac UK

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