



Message from the Editor

Welcome to the latest edition of the Volunteers' Update. In the office we are adjusting to life without Barbara and wish to thank everyone for all the lovely well wishes sent her way, she was incredibly touched by all. We are now recruiting for a new Volunteers' Assistant, more details of which below. Alongside recruitment we continue to look at our volunteering offering. Isobel has been busy launching two new campaigning roles focused on health and food respectively - read on to see how you can get involved.

Coralie has been updating the Member2Member packs and we will be providing more details on this service in the next edition of the Update. Meanwhile I've been reviewing Local Group governance - such fun! Building on last year's Local Group survey we have streamlined the Constitution and really value your feedback and suggestions on this. We will also be talking about the Constitution and more generally about what we ask of Local Groups at the regional Volunteers' Conferences. If you haven't yet booked your place please do so as soon as possible.

Finally we have two shout outs: to Jean Foster as a finalist in the Spirit of Cumbria Awards, and to South Surrey Member Len Clark who celebrates his 100th birthday next week. Our congratulations to both.

As always if you have any questions about any of the articles do not hesitate to get in touch by emailing volunteering@coeliac.org.uk

Happy reading, Miranda

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Events

Do you have the date in your diary? The Allergy & Free From Show North 2016

Attend for FREE with Coeliac UK

Bringing you more 'Free From' features than ever before, why not join us at the Allergy & Free From Show North, sponsored by Schar, on 5- 6 November at the Liverpool Exhibition Centre. The show is a great day out for the whole family and offers you the chance to try and buy a wide range of Free From foods, chat to Free From manufacturers and attend a range of talks on a variety of subjects. Our staff will also be at the show to answer any questions you may have about your Membership, coeliac disease and the gluten-free diet.

We would love to see as many of our Members there as possible so it would be fantastic if you could share the date with your Local Group Members as well as family and friends.

Coeliac UK has teamed up with the Allergy & Free From Show to give you unlimited free tickets to this year's event. Download free tickets at www.allergyshow.co.uk/go/CUKvolunteer

Regional Volunteers' Conferences booking reminder

Please find attached your Conference booking forms for [England](#) and [Scotland](#). If you haven't already done so please discuss with your Committee and return as soon as possible.

In addition to hearing about updates taking place within the Charity we will also be leading a discussion about the role of Local Groups. We are currently reviewing the Local Group Constitution so as to make it more streamlined (read more below). As per the Volunteer Survey last year Local Groups highlighted a wish for greater flexibility in how they go about running their events. We will build on both of these to ensure you and your Committee are in the best position possible as you carry out your events and activities. We will also be providing you with tools and template letters to help you further promote your Local Group and engage with Members.

Where:

York - Bar Convent, Saturday 10 September

Birmingham - Priory Rooms, Saturday 22 October

Reading - Reading University, Sunday 20 November

Scotland - Saturday 24 September, venue to be confirmed shortly

Cardiff - TBC by Tristan in the coming days

Each event will run from 10am-4pm and a simple lunch will be provided along with a number of tea and coffee breaks.

Happy 100th Birthday Len Clark

We wish to extend the very best wishes to Member Len Clark who has his 100th birthday in August. Len was born in Islington and after passing the scholarship exams at 11 he went to Highbury County School. On leaving he worked for the London County. Len has always had a major interest in walking and cycling, shared by his family and he became Regional Chairman of the National Trust in addition to Chairman of the Youth Hostels Association.

In 2002, after being ill for an extremely long time, Len was diagnosed with coeliac disease and subsequently joined the South Surrey Local Group, which he continues to support to this day. To celebrate his birthday the Local Group baked him a gluten-free birthday cake.

Happy birthday Len – we wish you and any other Member celebrating their 100th birthday this year many, many happy returns!

Flood hero, Jean

We were delighted to hear that Jean Foster, Group Organiser for the North, East and West Cumbria Local Group was a finalist in the Spirit of Cumbria Awards for the fantastic contribution she made after Storm Desmond. By linking with a range of manufacturers Jean coordinated gluten-free food collections in support of the local flood recovery work. Jean won tickets to see Rod Stewart in concert as well as being treated to a fabulous meal.

Coeliac UK would like to extend huge congratulations to Jean Foster and all the volunteers supporting her. We are humbled by the fantastic support and help given by all.

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

- 10 September 2016 - South East Hants food fair
- 8 October 2016 - Penrith food fair
- 15 October 2016 - Hereford food fair
- 15 October 2016 - Peterborough food fair
- 22 October 2016 - West Sussex food fair
- 19 November 2016 - Bath and West Wilts food fair
- 26 November 2016 - Calderdale and Huddersfield food fair
- 26 November 2016 - Belfast food fair

Please visit our website for timings and addresses for [food fairs](#).

2017 food fairs and Coeliac UK events

Dates are already being booked up for food fairs next year (see below):

- 4 March 2017 - Wirral food fair
- 25 March 2017 - Leeds food fair
- 1 April 2017 - Dorchester food fair
- 10 June 2017 - South Wiltshire food fair
- 17 June 2017 - Birmingham food fair
- 23 September 2017 - Beds and Mid Herts food fair

To ensure no clashes between Local Groups please note the following dates have already been taken:

- 24 June 2017 – Coeliac UK AGM
- 7 October 2017 - Volunteers' Conference, Birmingham



Crossed Grain deadline

If you would like your Local Group event to be listed in the autumn edition of Crossed Grain please make sure you send through the following information to volunteering@coeliac.org.uk by 12 August.

Date of event

Type of event

Timing

Location including postcode.

We will only list events where we have full information.

New volunteering opportunities to make a difference

Become a Food Campaigner

It is fantastic to see so many of you signing up for our new Food Campaigner role, hopefully you have found the campaign pack interesting and useful! This opportunity has been launched to help improve your experience when food shopping or eating out gluten-free. Activities include providing tips to restaurants on gluten-free catering, taking part in our 'Mystery diner' initiative, to contacting your local retailers about expanding their gluten-free range. For more information and to sign up now visit www.coeliac.org.uk/foodcampaigner

Become a Health Campaigner

This summer we are excited to relaunch our Health Campaigner role with a new campaign pack to give you the information, activities and tools to make a real difference locally. Our Health Campaigners will be involved in activities such as joining patient feedback sessions and liaising

with dentists and pharmacists to raise awareness of the condition and improve diagnosis rates. If you are interested in signing up as a Health Campaigner please visit www.coeliac.org.uk/healthcampaigner

If you would like more information about either of these roles to include in your newsletters then please contact us at volunteering@coeliac.org.uk

Moray food bank

During the Scottish Groups get together in November 2015, it was discussed how Local Groups can engage more effectively with groups, such as food banks, within their area. Following this we contacted the local food bank. The Manager was very interested in looking at ways that he could promote the work of the food bank and also engage with groups with special dietary needs, so he invited us to visit. The food bank have a staple bag which clients receive containing basics such as milk, tea, coffee, baking potatoes, tinned tuna, tinned fruit, cereal, pasta or rice, soups etc. They also have an area set aside in the food bank store for special dietary requirements e.g. gluten-free, dairy free etc.

We decided to make up a few readymade basic bags which have gluten-free alternatives in them which they can hand out to clients who require gluten-free food. In the first instance we provided them with three bags made up with a list on the side of the products included.

We dropped them off at the food bank and made an agreement that they could contact us when they had used up a few of the bags.

To find out more please read the full story [here](#).

Volunteer Team

The best way to contact the Volunteer 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

Isobel Ford, Volunteer Coordinator
9am – 5pm, Monday to Friday
Telephone number: 01494 796720

Local Group Governance



Constitution review

Following the Volunteer Survey last year in addition to various comments back from Local Groups and shared learning from other charities we are currently in the process of streamlining the Coeliac UK Local Voluntary Support Group Constitution. We have completed the first draft of this and it's now over to you – please review the [attached document](#) and feedback with your comments, any additional changes you would like to make, any areas you feel more or less detail is needed. Feedback should be sent to volunteering@coeliac.org.uk by Friday 23 September.

We will collate all feedback for further discussion at the regional events, with the aim of having the streamlined Constitution approved and ready for the 2017 AGMs.

Please note that we have removed the finance section which will be developed as a separate document accompanying the Constitution in light of the new financial set up – more details of such as soon as possible.

Social media

Promoting your Local Group events on social media is a fantastic way to raise the profile of your Local Group and to highlight that fantastic work being done by your Committee. Coeliac UK automatically promotes food fairs one month and one week before the event however, there are lots of other ways and opportunities for you to showcase what your Local Group is up to. Send us pictures of:

- you and Members at coffee mornings, meals out and Local Group meetings. Let us know where you are and how many people you have attending. It highlights to Members that you are active, friendly and welcoming
- the cakes and goodies you have purchased or baked ready for your Local Group event, alongside details of the event so people know where to go if they want to enjoy the food
- you surrounded by raffle prizes and goody bags prior to your event alongside details of the event
- a site visit for your food fair along with the date and time of the event
- you meeting with restaurant staff and agreeing the menu before a meal out
- you with your Committee at your next Committee Meeting letting us know what you are planning.

A photo and a few sentences about what you are doing is all you need to make your post interesting and relevant to readers. Such posts not only showcase the fantastic work being done by your Committee Members but also promote the work of Local Groups more generally across the Charity. What's more, photos of Members of all ages at events, smiling and enjoying

gluten-free food will help break down any myths people might have that Local Groups aren't relevant to them.

The Coeliac UK Facebook is followed by over 50,000 people, our Twitter account by 25,000 people – don't miss this opportunity to advertise and celebrate the fantastic work being done by your Committee and the support given by your Members whilst also attracting new Members to your events.

Please submit all posts for volunteering@coeliac.org.uk. We will notify you when they have been posted.

Welcome Bristol

We are delighted to announce that the new Bristol Local Group is now up and running. The Committee organised a fantastic launch event at a local primary school which was attended by over 80 Members, family and friends. The Committee did a great job liaising with manufacturers to organise goody bags which, combined with left over samples from the Coeliac UK AGM, meant everyone left with their arms full of gluten-free goodies. The raffle provided proved a great fundraiser putting the Local Group in a strong position as they start to plan future events. We extend a very warm welcome to the Committee and wish them the very best with their future events and activities.

We are currently working with several Local Groups to help them recruit a full Committee:

- Oxfordshire
- Tayside
- Highland
- West London.

Sadly we have recently seen the closure of the Guernsey, Tayside and North Surrey Local Groups. We are in the process of re-opening the Nottinghamshire Local Group and will be looking to do the same in Scarborough, Tayside and North Surrey as well as opening a completely new Local Group in Somerset before the end of the year. We will keep you updated on progress for each in the next edition of the Update.



News from Coeliac UK

Wishing Barbara the very best

Barbara Mayne left Coeliac UK at the beginning of July, thank you so much to all those who contacted her before she left. She was incredibly touched by all the messages and completely overwhelmed by the gifts. Barbara was very sad to be leaving the Charity and having to say

goodbye all the friends she has made over the past 16 years with the Charity. I know she will particularly miss all the sports banter that she enjoyed with many of you.

We are now recruiting for new member of the team: a full time Volunteers' Assistant based at the Charity on a 12 month contract. The advert runs until the end of this week and we will be conducting interviews the week commencing 15 August. We will keep you posted!

Is it coeliac disease? campaign hits Birmingham



We are now in year two of our *Is it coeliac disease?* diagnosis campaign which aims to help find the half a million people with undiagnosed coeliac disease. As part of the campaign, pop up outreach events have taken place in UK cities which many of you have very kindly supported. At each event campaign leaflets were distributed and local people were welcome to drop in and talk to

someone from Coeliac UK about the condition, their symptoms and steps to diagnosis.

I attended the event in Birmingham last month which was an exciting opportunity to raise awareness of coeliac disease and speak to the public and Members about the condition. I found it such a positive experience and it was particularly interesting to experience the difference in knowledge and understanding of coeliac disease. Some people refused to take a leaflet, others have had coeliac disease as long as they can remember, and some would look at the banners with the common symptoms and say "I suffer with these every day". Those who were reporting symptoms, have first degree relatives with coeliac disease or related conditions were offered an assessment and a point of care test.

Over the course of the week we provided testing for coeliac disease for 87 people using the Simtomax point of care test, with a positive result for around 12% of those who were tested. All those testing positive were referred to their GP for further investigation.

A special thank you to all those who have been involved in helping out at the pop ups events. It was great to meet some of you and a huge thanks for your incredible enthusiasm and support. From my point of view the event highlighted the fantastic work that the Local Groups and our incredible volunteers do to raise awareness and the impact it has on so many people! Please keep doing what you are doing.

The next and final stop for the pop up events is Newcastle which will be taking place 15-19 August!

- Isobel, Volunteers' Coordinator

Update on gluten-free prescribing

We continue to campaign on gluten-free prescribing at both a national and local level. Currently the majority (63%) of National Health Service Clinical Commissioning Groups (CCGs) continue to follow National Prescribing Guidelines for gluten-free prescribing. All Health Boards in

Scotland and Wales follow national prescribing guidelines. However, we are aware that some CCGs have either restricted (30%) or in some cases withdrawn (7%) access to gluten-free food on prescription.

We have been continuing to make the case for gluten-free prescribing to CCGs that have introduced restrictive policies and to CCGs that are consulting on removal of gluten-free prescribing. We have gained the support of the British Society of Gastroenterology and the British Dietetic Association.

We have been contacting individual Members in areas affected to provide information on any policy change and to advise how Members can make their voice heard, locally. We have also been contacting Members to inform people of local consultations to engage and have their say.

In areas where restrictions have been placed we have been contacting local Healthcare Professionals and local Healthwatch asking for their support. We are also raising the issue on gluten-free prescribing with local MPs.

Update on the current situation

In the last six months, 20 CCGs have consulted on gluten-free prescribing. The following CCG consultations are currently open;

- [Kernow CCG](#)
- [Sunderland CCG](#)
- [Wirral CCG](#)
- [Bradford Districts and Bradford City Clinical Commissioning Groups \(CCG\)](#)
- [Basildon and Brentwood CCG](#)

We also have updates on a number of CCGs that have reviewed their local policy on gluten-free prescribing;

- [Hambleton Richmondshire and Whitby](#)
- [Heywood, Middleton and Rochdale CCG](#)
- [Southend CCG and Castle Point and Rochford CCG](#)
- [South Devon and Torbay CCG](#)
- [Bury CCG](#)
- [North East Lincolnshire CCG](#)

We will continue to campaign on gluten-free prescribing and aim to keep everyone updated on any open consultation, or local review of gluten-free prescribing policy as we hear more.

Please [keep us updated](#) if you are made aware of any consultation on gluten-free prescribing in your area, or if you are aware of any local changes to gluten-free prescribing.

Patient View

We know that Local Groups are often contacted by research companies seeking personal insight into living with coeliac disease and being on a gluten-free diet. Where surveys have

been developed in line with Coeliac UK we will also promote on our website and through our monthly newsletter.

Patient View has sent a number of emails to Local Groups over the past year on various different topics. We've noticed that in recent surveys not only are they asking for your personal opinions but also more widely on the role and views of your organisation. What's more the topics being surveyed are not always specific or even relevant to coeliac disease. As such we are asking Local Groups not to take part in any of the projects being circulated by Patient View.



Mum's Kitchen is a lovely new family run kiosk in Kingston-upon-Thames. All their products are made from scratch, using natural ingredients and are derived from the long lasting traditions of Armenian and Russian cultures. They aim to satisfy customers with dietary requirements with their dairy, sugar and gluten-free options. Mum's Kitchen Kiosk is at the Eden Walk Shopping Centre, outside M&S and Boots www.mumskitchen.london/



Celebrating Fish & Chips is the motto of Fraser's Fish & Chips. Located right on the prom in Penzance (Cornwall) this award winning fish and chip shop is more than just a chippie. Gluten-free fish and chips are available daily to be enjoyed in their restaurant or from the takeaway. With only sustainable fish on the menu and Cornish fish specials daily, coupled with award winning chips it's well worth a visit. www.frasersfishandchips.co.uk

When you see the Coeliac UK GF logo you know that the restaurant is adhering to our Gluten-free standard. The standard covers all aspects of gluten-free preparation as well as ensuring training is in place so you can eat out with confidence, knowing that we've worked with the venue.

See the full list of organisations that have gained our accreditation on our website www.coeliac.org.uk/GFaccrreditation



We'd love to hear from you!

volunteering@coeliac.org.uk / 01494 796118