



## Message from the Editor

Season's greetings from us to you!

Thank you all for another fantastic year of volunteering. From direct support to the newly diagnosed, to hosting highly praised events for Members to raising awareness as part of your Charity's national campaign work we remain grateful for and deeply impressed by the amazing commitment and support you show.

It has been really wonderful seeing so many of you at the regional events held over the past few months. The events showcased not only the work being done by Coeliac UK but also the huge amount of experience and knowledge inside each committee. At the conference we looked in detail at the revised Local Group Constitution and Finance Policy as well as updating everyone on the work being done to improve people's awareness of coeliac disease and the work we all do - volunteers and staff alike, to support those living gluten-free. There is much more detail on this below. Please make sure you read!

Finally, with AGM planning in full swing in the New Year we continue our series of articles on volunteer recruitment. If you need any further support with recruitment please do not hesitate to get in touch with the Team.

Wishing you all a very Merry Christmas, a splendid festive season and a Happy New Year, happy reading! Miranda

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All presentations can be found under “Guidance” in the Local Group admin section on the Coeliac UK website.

We’ve had an absolutely wonderful time meeting so many of our volunteers at the recent regional conferences taking place in York, Birmingham, Reading and Edinburgh. Thank you to everyone who gave up their weekend to sit in a room with me! I had a blast! I don’t think we’ve ever had such lively and engaging conversations as this year. From debating issues around prescriptions to discussing challenges and celebrating successes, it was fantastic to see everyone participating, sharing their stories and learning from each other. Thank you.

All conferences followed a similar agenda, including:

- an update from Coeliac UK
- a look at the Local Group Constitution and Finance policy
- guidance on recruiting new Committee Members
- updates to the Venue Guide and Recipe database
- the Charity’s Member engagement programme and new branding.

A prescriptions update also took place at the events in England whilst a Scotland update was given by Myles Fitt at the Edinburgh conference. The Wales Conference has been moved to the New Year where Members will hear directly from Tristan Humphreys on developments there.

### **Update from Coeliac UK**

For the past two years Coeliac UK, supported by our Members and volunteers, has been campaigning like never before as we look to reach the half a million people in the UK still to be diagnosed with coeliac disease. From promoting our online assessment to working with our patron Caroline Quentin to promote the *Is it coeliac disease?* diagnosis campaign through the media. During Awareness Week we sent leaflets to over 6,000 GP surgeries with info ads also going in 1,500 surgeries and our volunteers helped spread the word too on our National Leafleting Day when over 10,000 leaflets were distributed. With the help of local volunteers the Charity handed out an additional 25,000 leaflets at pop up events and further engagement also took place through our social media campaign. We are incredibly grateful to everyone who supported the campaign.

The *Is it coeliac disease?* diagnosis campaign will keep running into 2017 as we continue to work towards our long term goal confirming a diagnosis for an additional 250,000 people by

2020 so that they are freed from not knowing what is causing their symptoms, pain and suffering.

Next year we will also be campaigning for better access to gluten-free food. More information can be found below in the article on Awareness Week but rest assured there will be plenty of opportunities for everyone to support this important campaign.

What's more, we will continue to campaign against prescription cuts taking place in the UK. Again, further information below.

Over the past year we have also been looking in great detail at the Charity's position, value and relationship with Members. As a result of this work we are excited to be revealing a new look in 2017 which will be accompanied by a step change in how we operate, as we celebrate our Members and continue to strive for a better world for people on a gluten-free diet.

Finally, 2016 has also seen large changes within the volunteering team, with Miranda's return to the office in April and the very sad news of Barbara retiring in July. (We still haven't forgiven her!) The great news for you is there is now more support being given to our volunteers with both Bharpur and Isobel working full time and Coralie and Miranda also helping out. This year has seen two new volunteering roles being launched, the development of the Member 2 Member volunteering programme, the establishment of new Local Group Committees and an unprecedented level of support being given to the recruitment of new Committee Members – with fantastic results across the UK. It's been a busy year and we're all really looking forward to working with you again and further improving our support for you in 2017.

## **Prescriptions**

Following a strict gluten-free diet for life is the only treatment for people with coeliac disease. As Clinical Commissioning Groups (CCGs) across England make cuts to gluten-free prescriptions, we're continuing to campaign to protect these vital services and to make sure that the voices of patients are heard and considered in local decision making. Crucial to this is the active involvement of Members. Where local consultations are being launched, we have been contacting local Members by post, email and using social media to ensure you have the chance to have your voice heard by completing consultation surveys. Only by as many of us as possible making the case for gluten-free prescribing can we fight for this vital service.

In October the first ever Quality Standard on coeliac disease was published by the National Institute of Health and Care Excellence. The new standard sets out five key areas to improve diagnosis and ensure that the support of patients with the condition improves their health and quality of life. Both offering an annual review and having access to prescriptions for gluten-free food are noted as important levels of support for people with the condition. In light of 10% of England's Clinical Commissioning Groups (CCGs) removing gluten-free prescribing as a support for those with the condition, Coeliac UK is writing to all CCGs to make them aware of the new quality standard and to ask how they plan to meet its criteria.

Last month, there was a Westminster Hall debate in the House of Commons, secured by Kevan Jones MP for North Durham and Chairman of our Cross Party Group on coeliac disease and

DH. There was good attendance from MPs who came armed with personal stories from their constituents which made for a good debate and intervention on behalf of those with coeliac disease. At the closing of the meeting, David Mowat MP, the Parliamentary Under Secretary of State at the Department of Health said: "CCGs should not withdraw gluten-free products without a consultation. My understanding is that in all cases where that has happened, a consultation has taken place. If [you] can provide me with evidence of that not being so, I will follow up and take action. The information I have been given is that consultations should always have taken place. Finally, there is the issue of the postcode lottery. It is true that we give CCGs a lot of power in our system in terms of making clinical decisions. The idea behind this is that they look at local considerations and balance the various options that they have. However, I will see to it that a review is done, hopefully within the next six months, of prescribing policies, and we will endeavour to come together with something that is more consistent, in a way that means we can actually progress on this."

We extend a big thank you to all our Members and supporters who contacted their MP to attend and help make our voices heard.

### ***Developments in Somerset***

Somerset CCG's proposal policy to ban all gluten-free prescriptions is unique in its extreme nature and failure to protect vulnerable patients, which in our opinion is a breach of statutory duty and merits a more formal challenge. As a result we have sought legal advice and instructed a solicitor to write to the CCG on our behalf – we are still awaiting a response and will update you in the New Year.

### **New Constitution and Finance policy**

As I hope you are, by now, all aware, we have been doing a fair bit of work around the Local Group bank accounts. Triggered by difficulties with CAF bank and the need for more robust banking process with greater checks and accountability we are now in the process of moving over to Lloyds.

### ***Lloyds bank account update***

Thank you to everyone who has signed and returned their signatory form. This is the very first step in setting up your new account. Lloyds have now started the authentication process and you will shortly be hearing from us again providing instructions on how to finalise the signatory process (namely to visit your local Lloyds branch with ID) and how to close your bank account.

Your Lloyds bank account will not be fully useable until the full, two-part signatory process has been completed. We strongly advise you to continue using CAF as your primary bank account until you hear otherwise from us.

### ***The Paperwork***

In an effort to streamline and ensure that all our paperwork matches the recent changes of governance the Board of Governors have ended the year by signing off an updated [Local Group Constitution](#) and new [Finance, Fraud and Fundraising Policy](#).

Further changes to the [Constitution](#) will take place next year in light of the Investing in

Volunteering award. Please however make sure you do read this version (attached) and that all your Committee are happy with it come your 2017 AGM. If you have any questions about the Constitution please do not hesitate to get in touch.

[The Finance, Fraud and Fundraising policy](#) has been developed to provide a one-stop shop for all legal financial requirements and best practice for Local Groups. In addition to moving the finance section out of the Constitution and into this document we have also added a new fraud policy and further guidance when fundraising to ensure you are up to date and confident.

Paper copies of both documents will be sent out to all Group Organisers and Group Treasurers in the New Year.

## **Member engagement: a new look for Coeliac UK**

### **Launching a new look for the Charity in 2017**

We are delighted to be launching a fresh new look for the Charity in 2017 and wanted to let you know what this means for the Local Groups.

We have been talking to many of you over the past 12 months about the challenges facing the Charity as we look to extend our reach and support. We know that a more visible public profile and a more engaging service offering, particularly online, are some of the improvements we need to make to grow our community. Thank you to all those who contributed to this discussion at the regional Volunteer Conferences.

As you may also know, we asked past and present Members to help us select a suitable image in October through our online brand survey. Our new look is based on the feedback we received and has reassured us that our new image appeals to the majority of our Membership and how they feel about living gluten-free.

### ***How the new look affects Local Groups***

We are planning a 12 month roll out of our new look, starting in January. You will see it applied to our email newsletter, 2017 edition of the Food and Drink Directory and our website by the end of January. It will be gradually applied to other materials over the course of the year to manage resources, costs and reduce waste.

As part of this new Local Group logos are currently being developed and will be with you by the start of February! We will then work with you to have your materials and merchandise updated and to ensure you are confident with the new look.

This is an exciting opportunity to develop a dynamic, consistent image across all our public materials to increase awareness of the Charity and the work we do at a national and local level.

Please note that as part of this we will be freezing our website for one week in the middle of January as we introduce the new look. During this period you will need to contact the Volunteer Team for access to your Membership lists and to add or remove content. We will give you further information in the New Year on this.



## Events

### **Hereford Local Group**

The Local Group's two longest serving Committee Members Alan and Cathy Holmes stepped down at the food fair after nine years of service. Cathy has organised eight food fairs during this time, and both have offered their friendship and support to countless newly diagnosed patients.

The Committee and Coeliac UK will miss them greatly but wish them all the best for the future.

### **Sevenoaks Local Group**

#### **Alison Batchelor 1950 – 2016**

It is with great sadness that we inform you of the death of our Committee Member Alison Batchelor. Alison joined the Sevenoaks Local Group Committee in the spring of 2010 and later took on the role of Web Master, sending out regular information emails of news and events to all our Coeliac UK Members. Alison was the contact for all the newly diagnosed. She enjoyed baking cakes for events and was always coming up with new ideas, especially where our younger Members were concerned, helping them ice and decorate their own cupcakes to eat at the children's parties.

Although Alison hadn't been well over the last couple of years she always had a smile for everyone at the signing in table when welcoming Members at Local Group meetings. Alison also enjoyed attending our monthly coffee mornings.

Our very dear friend will be greatly missed.

### **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](#).

### **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
- 1 April 2017 - East Lancs and Preston food fair
- 22 April 2017 - Bristol food fair
- 29 April 2017 - Bournemouth and Poole food fair
- 13 May 2017 - York food fair
- 3 June 2017 Lincolnshire food fair

- 10 June 2017 - South Wiltshire 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
- 11 November 2017 - Hereford food fair

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

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



### **Awareness Week, Monday 8 - Sunday 14 May 2017**

Next year's Awareness Week will be all about food! We will be working with restaurants and venues to promote our catering training module and gluten-free accreditation scheme as we raise awareness and enhance the eating out experience for those on a gluten-free diet. We will be working with supermarkets to further the gluten-free guarantee which marks a commitment from supermarkets on the availability of products. We will also be addressing food on the move, looking at improvements in availability, choice and affordability when travelling by plane or train, visiting sports and entertainment venues and in schools, hospitals and care homes. Most importantly of all, we will be working with you.

As always we will be sending out packs filled with information to volunteers and our Local Groups with lots of ideas and supporting materials so you can educate others and speak out locally. Full information on the campaign will come out in spring Crossed Grain. In the meantime, start thinking about what you can do:

- challenge a take away venue to cater for one of your Local Group meetings (double up with a quiz and raise funds at the same time)
- host a lunch for Members at a local catering college
- organise a stand during Awareness Week at your local supermarket
- hold a meeting with the hospital dietetic department and talk to them about how patients with coeliac disease are catered for
- host a gluten-free bake sale at your child's school.

## **Mystery Diner**

**Do you eat out regularly? Help us to improve our services by providing feedback on your dining experiences.**

As part of the Food Campaigner role we would like people to take part in a 'mystery diner' activity to support Coeliac UK's continuing improvement of the GF catering accreditation scheme. We are looking for feedback from people dining out at our accredited venues. While we are looking for feedback on 14 of the accredited venues, if you don't normally eat there we do not expect you to make a special visit. However if you are eating out in the venues listed below, we'd love to hear about your experiences!

- Carluccio's
- Domino's
- Ed's Easy Diner
- Frankie & Benny's
- Pizza Express
- Côte
- Pizza Hut
- Prezzo
- Handmade Burger Co.
- Hard Rock Café
- Harrods
- Pho
- Wadworth & Co Ltd Pubs (there are 45 accredited Wadworth pubs, to find your nearest one visit the Venue Guide [www.coeliac.org.uk/venues](http://www.coeliac.org.uk/venues))
- Filmore and Union

The survey should take no more than ten minutes to fill in after your visit. If you are willing to take part please visit [www.coeliac.org.uk/mysterydiner](http://www.coeliac.org.uk/mysterydiner) for more information. Many thanks for your support.

## **Donate your stamps**

You can now donate your used stamps to raise much needed funds. All kinds of stamps are welcome, on or off paper. Simply cut or carefully rip the postage stamp from the used envelope, being careful that you don't damage the stamp, and once you have a collection pop them in an envelope making sure you have the correct postage to:

COELIAC UK  
PO Box 16992  
Sutton Coldfield  
B73 9YA

\* Please include postage when sending stamps \*

## **Give As You Live**

Did you know that you can support Coeliac UK by shopping without spending any extra pennies? Register with Give As You Live and nominate Coeliac UK as your chosen charity and



shop away.

[www.coeliac.org.uk/get-involved/support-us/give-as-you-live/](http://www.coeliac.org.uk/get-involved/support-us/give-as-you-live/)

## Investors in Volunteering

Next year the Volunteer Team will be embarking on the Investors in Volunteering scheme. This is a UK quality standard highlighting the importance of volunteers that works with organisations to ensure an outstanding volunteer experience. It will allow Coeliac UK to benchmark the quality of our volunteer management, good practice and involvement of volunteers as well as pushing us to improve the effectiveness of our work with volunteers, enhancing our overall reputation.

Over the course of the next six to twelve months we'll be working with the assessors to:

- identify weak spots
- refresh our policies
- become more thorough in our good practice
- raise awareness about the importance of our volunteers and the role they play within the organisation
- and ensure a robust framework for future action.

More information on the scheme can be found

at: <http://iiv.investinginvolunteers.org.uk/about/the-nine-indicators>.

## Gluten-free Christmas

Our Christmas list is now available, listing lots of gluten-free treats you can safely enjoy this festive season. [Download a copy now](#) and visit our [Christmas page](#) for hints and tips for enjoying a gluten-free Christmas and some tried and tested festive recipes.



## Recruitment

### Part two - Recruiting volunteers

Following on from the October Volunteers' Update you've started your recruitment process and have identified a number of people who are potentially interested in volunteering so what do you need to do next?

Make sure you give key information to any interested people, the key information being:

- a role description (simple overview of the role and the tasks it entails)
- background information about your Local Group and Coeliac UK
- an explanation of the recruitment process i.e. what happens next.

Don't panic – you don't need to be writing pages of text, just a couple lines on each is all that's needed.

### **Have a good ol' chat**

So you've given people the key information and they're still interested in volunteering, what next?

Firstly, you need to meet them and they need to meet you. The point isn't to make potential volunteers feel nervous, put them on the spot and perhaps catch them out. You want to give the person the best opportunity to talk about themselves and why they want to volunteer and make sure that they know what being a Local Group Committee Member is all about. Try to avoid the model of firing questions over a desk. This should be friendly, informal and informative for both sides.

### **What do you need to know?**

In some cases this will simply be a little about the person's background, what skills they have, and why they want to carry out the role. You should also ensure that they have a decent idea of what the role entails. Questions about following policies and principles might be sensible – some people believe that being a volunteer means they don't have to turn up on time, or that they don't need to concern themselves with equalities policies.

Other questions might be more specific to the activities they'll be carrying out. Find out what motivates them – this is important for you because if a volunteer's motivations aren't met by their role they are unlikely to stay beyond the short term, or at least not give the effort they otherwise might. Actually, it may be that the role isn't suitable or you may have other roles that would offer what they were looking for. Or, you could alter the role to better suit them. For example, if they are looking for good work experience you might decide to give them a rolling programme of tasks. Best to find out now rather than wasting your time and theirs trying to fit them into something unsuitable.

You should also make a list of the information you want to give potential volunteers. Some people will have lots of questions, but others might still be a little intimidated, even if you have tried to make the process as welcoming as possible. The aim is to give them enough information for them to be able to make an informed decision about whether they want to volunteer. The process should be about both of you making a decision, not just yourself as a recruiter.

### **How should we choose volunteers?**

Selection should be fair and reasonable. Remember, you are rarely looking for the 'best' potential volunteer. The key question should be 'can this person carry out the role, given the level of training and support we can offer?' Your role description should give you a good framework for determining this. Where possible try to be flexible. For example, a person with a lack of confidence might not be able to carry out every aspect of a role at first – you may well be able to accommodate this. On the other hand do be conscious of the level of support you can provide. If someone will need more help than you can offer then you will not be assisting them by taking them on.

Other considerations might be:

The person's reasons for volunteering and attitude to the role – if someone wants to volunteer because they're looking for something social and you know that most of the time they'll be on their own, then the role probably isn't right for them. And if the potential volunteer doesn't seem too enthusiastic about the role itself but just wants something to do you might feel they aren't right for you.

Their willingness to follow procedures – some people imagine as it's voluntary work they can do more or less as they please. It's not quite enough just to give somebody a policy on diversity or confidentiality, attitudes matter. We aren't asking for an academic understanding of charity law but a sense that that they are willing to learn, follow guidelines, and understand why the issue is important.

### **How do we say no?**

This is always going to be awkward, as of course people are offering you their time. Firstly remember that you do have the right to say no. You are not duty bound to take on any potential volunteer, although you should of course satisfy yourself that you have good grounds for doing so. Be honest (without being hurtful). You are not doing the applicant any favours if they keep applying for roles that are not right for them. Where possible, offer alternatives. You might have other roles that are better suited to them. Failing that direct them to other organisations you're aware of that might have roles for them.

### **Can we offer a trial period?**

We tend to call them taster periods, and they can be a good idea. 'Taster' rather than 'trial' period is a less off-putting phrase, but it also shows a slight change in emphasis. They allow volunteers the chance to give the role a go in the knowledge that they can back out at the end of the period without feeling they have let anyone down. They also give you the chance to see the volunteer in action.



#### **Café Caldesi**

Caffe Caldesi bar and restaurant in Marylebone serves traditional and modern Italian food. We are happy to announce they have now gained GF accreditation and have launched a new gluten-free menu. Since Giancarlo Caldesi discovered his intolerance for gluten they've been committed to safely serving people with coeliac disease.

Pop in for a coffee and gluten-free cake or even enjoy a three course meal.



### Creperie

The Creperie is the first totally gluten-free restaurant in Brighton. They are fully committed to providing their customers an environment completely gluten-free. They offer delicious Galettes, Crepes, Wraps and Waffles. Their most popular dishes are the 'Posh Cheese and Onion' which has fresh spinach leaves, caramelised onions and goats cheese and the 'Nutty Ella' which has lashings of Nutella.



### Scotts Fish and Chips

Scotts Fish and Chips own two multi award winning, eat in or takeaway, gluten-free, fish and chip shops in Helmsley and Bilbrough near York. Not only do they offer GF fish and chips, but also a range of starters, mains and puddings can be had! We're proud to announce that Scotts Fish and Chips and Scotts of Helmsley are now both accredited with Coeliac UK and we wish them the best of luck with their GF menu!

[scottsfishandchips.co.uk](http://scottsfishandchips.co.uk)



### Pumpkin Brown

Pumpkin Brown café in Edinburgh takes health and nutrition very seriously. Catering for a whole range of food intolerances including dairy and gluten-free, without compromising on taste. We are pleased to announce that they have now become GF accredited with Coeliac UK so you can enjoy their range of tasty meals safe in the knowledge that their food contains no refined sugar, no dairy and most importantly, no gluten. Bliss!

[www.pumpkinbrown.com](http://www.pumpkinbrown.com)



### Northumbria University - CCE Restaurant

taste Northumbria have recently achieved GF accreditation at their CCE Restaurant on Northumbria University campus. This makes Northumbria the fourth University in the UK to become GF accredited. taste Northumbria have worked hard to develop new gluten-free options for their

menus to better cater for those with coeliac disease in order to make the transition to University life easier than ever.

[sharethelove.co.uk/northumbria-home](http://sharethelove.co.uk/northumbria-home)



### **The Duke of Edinburgh**

The Duke of Edinburgh pub in Maidstone, Kent thrives on being relaxed and informal. It promotes an environment where coeliac customers can dine with peace of mind by running a 100% gluten-free restaurant. They are now the latest pub to be accredited with Coeliac UK, even making the shortlist for the Free From Eating Out Awards 2016 in the Independent Pub Restaurant category!

[www.dukeofedinburghbarming.co.uk](http://www.dukeofedinburghbarming.co.uk)



We'd love to hear from you!

[volunteering@coeliac.org.uk](mailto:volunteering@coeliac.org.uk) / 01494 796118

### **Volunteer Team**

The best way to contact the Volunteer Team is by emailing [volunteering@coeliac.org.uk](mailto: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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