# YORK LOCAL GROUP Newsletter May 2023



#### Welcome to our latest newsletter

A note from your Newsletter editor:

Hello, I hope you are all well and enjoying the longer days.

There is an important announcement from our group organiser Linda on page 2. We shall miss Linda's energy, but hope we can find someone who will lead us forward.

Our next coffee morning is on Monday June 5<sup>th</sup>, at the Hungate reading hub on Stonebow in York. See page 7 for further details, plus some changes in the way we are organising coffee mornings.

Please send any items for inclusion in future newsletters to <a href="mailto:york@coeliac.org.uk">york@coeliac.org.uk</a>

Best wishes, Sue

# York Coeliac Group Committee Officers

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## Big changes for your Local Group - and a challenge!

There are big changes ahead for your local group, and for me! On Boxing Day last year, while staying with our daughter in Ely, we chanced upon a house that was for sale. It was empty and we had a poke around, peering through windows and admiring the large garden. It was appealing but we thought no more of it. On the day after Boxing Day, our journey back to York took four and a half hours instead of the usual three. We commented that many journeys that we make to see our family seem to be taking much longer than they should. At the end of January, we were back in Ely and the house was still for sale.

After much thought, we decided to go for it. We have lived in York for twenty-nine years and have loved every moment, but all our family live in the south or midlands and we are not near to any of them! We thought we would see if we could get a buyer for our house and we did quite quickly!

Of course, moving house is always fraught with difficulties, but things are progressing, so we are hopeful of a move this summer. I am, therefore, going to step down as group organizer, with great sadness. It has been a privilege to run the group, and I have made so many friends and enjoyed many good times with you all.

I invite anyone who may wish to join the committee or become group organiser to get in touch with me. I can explain what might be involved.

Linda Deadman

# A message about future newsletters and membership of Coeliac UK

We are all feeling the pinch of the cost-of-living crisis, and as the York local group we need to reduce costs and streamline processes. With this in mind, your committee has taken the difficult decision that this will be the last printed edition of the York local group newsletter.

We still want to keep in touch with all of our gluten free community, and will continue to send out our news and events by email. If we do not currently contact you by email, you need to ensure that your email address is registered with Coeliac UK, and that you have given your permission to be contacted by email by your local group. If you are a member of Coeliac UK this can be done easily by logging on to your online account, checking your email address is correct and checking that you have given permission for us to email you. Members of Coeliac UK who receive information through the post will find details of York local group events in the insert in Crossed Grain.

If you are not a member of Coeliac UK please do consider joining: simply call the below number, or visit <a href="https://www.coeliac.org.uk">www.coeliac.org.uk</a> to find out more.

If membership isn't right for you now, but you would still like to hear from the York local group then please call Coeliac UK on the number below and they can add your preferred email address to their records so we can add you to our mailing list.

If you are unable to access email perhaps a member of the family or friend would be able to receive our information and pass it on to you?

Please remember that you are never alone in our community. Coeliac UK is here to support you so do get in touch with them on **0333 332 2033** with any questions, concerns or feedback.

#### **Coeliac UK News**

# Cost of Gluten Free Food: Affordability and Accessibility Campaign

We've launched a campaign for more affordable and more accessible gluten free food and we'd like all of our local groups to get involved, help raise awareness and get our voices heard.

# Join our Wall of Support

One important way you can help, is by sending a headshot photo to be added to our Wall of Support. We're using the community of faces online to demonstrate the level of support for our campaign and drive awareness of the cost of maintaining a gluten free diet. Once you pledge your support you'll receive email updates on the progress of the campaign and other ways you can help throughout 2023.

Find out how you can get involved and pledge your support: <a href="https://www.coeliac.org.uk/get-involved/campaign-with-us/cost-access-and-availability-of-gluten-free-food/">https://www.coeliac.org.uk/get-involved/campaign-with-us/cost-access-and-availability-of-gluten-free-food/</a>

# **Access and Availability Citizen Science Project**

As part of our cost of living campaign, we want to know about access and availability of gluten free products at your local supermarkets, alongside cost. Our findings will be published in a second cost report later in the year.

The aim of this project is to build a picture of the availability of gluten free products at your local stores and capture your personal experiences of shopping gluten free which will provide useful and relevant information to support our engagement with the food industry during Phase 2 of our cost of living campaign, help us to improve our services and bring change that is important to you.

This will be a citizen science project where members of our community visit their local store(s) and complete a survey on availability of gluten free bread and other key staple gluten free products. This can be completed as many times as possible over a specified period. We want to capture as much information from as many different stores as possible on different days and times from across the UK.

We are currently developing the project and testing the surveys with the aim to launch the access and availability project by Volunteers' Week (1-7 June 2023). If you would like to register your interest to take part, you can do so here: https://bit.ly/3LC5Vcv

# Coeliac UK News (cont'd)

# Have you or your child had a reaction to food or drink, or have narrowly avoided having a reaction in the last 5 years?

The Food Standards Agency (the food regulator for England, Northern Ireland and Wales) wants to understand the experiences of people who have had reactions to food or drinks or have narrowly avoided having a reaction, within the past five years. If you would like to share your experience, the survey will take around 20 minutes and your responses will be anonymous:

- Adults with coeliac disease and/or allergies/intolerance: https://bit.ly/3Hi0kWb
- Parents of children 0-17 with coeliac disease and/or allergies/intolerance: https://bit.ly/40L0IUb

## My food revolution: how I learned to love a gluten-free diet

After years of pain, the diagnosis of coeliac disease was a crucial turning point for Lizzy Davies, a journalist for the Guardian newspaper. In her article of 18<sup>th</sup> March, she explained the changes it forced her to make – and how she learned to love food once again

Unfortunately, the copyright rules of the Guardian will not permit us to print the whole article. But you can read it online at <a href="https://bit.ly/423qC6H">https://bit.ly/423qC6H</a>

#### Bishop Wilton Festival – with gluten free food

Member Chris Watson's wife Hazel will be selling gluten free goodies on a stall at the annual Bishop Wilton Festival, on Saturday  $20^{th}$  and Sunday  $21^{st}$  May. The event will be in St Edith's Church from 10am to 5pm. The entry fee, payable on the door, is £5 per person. You may also be interested in viewing the church's floor which apparently is a replica of that at the Sistine Chapel in Rome!

# Review of Gluten-free Afternoon Tea at Ashfield's restaurant, York College on 9th March

Report from Lynda Moody:

A group of 24 of us met at Ashfields Restaurant for a gluten free Afternoon Tea. The tea consisted of gluten free sandwiches, cakes, jam and cream scones. It was all delicious. We had a choice of either tea or coffee with our afternoon tea and we could have refills if we wanted. For the cost of £12 per person, I thought it was very good value for money. If any of us had any leftovers the staff kindly boxed them up for us to take home. I think a good time was had by all.

# How does my local group help?

Here is a thought-provoking piece from a Volunteer in the north-west of England (anonymous).

When you join or start to support an organisation, you don't always know where your journey will take you or what, if anything, you can do that will make a difference.

When our son was diagnosed with coeliac disease at the age of two, some 11 years ago, I felt that I needed to share what knowledge I had on cooking and baking with others. I knew that that would make a difference to some, especially those close to me, so that they too could make small changes to accommodate us. It's amazing the small impact of those changes, made to us as a family: enabling us to be more inclusive and not to single any one family member out just because they have a diet that is seemingly limited.

We did of course sign up to Coeliac UK. The bigger picture of research and family support and the support for others, was then something that I wanted to be part of. To ensure the future of others and that those suffering on the side-lines could, at least, be made aware of symptoms, often undiagnosed and get them treated. I wanted to be part of that process and that support.

Which is when heard about the local support groups: similar people, suffering from coeliac disease and equally having to live a life without gluten. We attended our first meeting, as a family, in a community centre (I'm sure like others) in Middlewich, Cheshire. Hoping to find others like us – a family of 4, with 2 younger children.....We were a little under-whelmed on our first visit – I think we were the only family there and definitely the only ones there with children under the age of 10! But families are diverse and now we are part of a much wider family, of people with an understanding of what it's like to live without gluten. It was an interesting first impression.

Later meetings unfolded and it became apparent that the Cheshire Group were looking for a new Group Organiser. Someone to lead a committee and local members to share experiences and knowledge of how best to live a gluten free life. I stepped up. If by some chance, I could make a difference to someone's life by sharing our experience with a wider audience then, I would take that chance. The Group accepted my application. An acceptance, that even now, I am very grateful for. For the opportunity to share and to lead a wonderful group of people.

And it could finish there. But it doesn't and it won't. We never really know the impact we make. We never really know, who is taking notes, watching and learning from what we do and how we do it.

During my limited time as Group Organiser for the Cheshire Group, we held two or three large meetings across the county, speakers were booked, small stall holders were booked, nurses turned up and cookery demonstrations were given and even a couple of coffee mornings! Surveys were handed out so that we could move the Group forward and try to support the variety and diversity of our members. You talk and you network, the work of a supporter doesn't stop. You don't know who might need the information you hold, that could save time, money or a life. Our membership stretched further than Cheshire, as other local Groups had either folded or didn't exist. Staffordshire, Greater Manchester, Derbyshire and even Shropshire.

# **How does my local group help?** (cont'd)

So when there came a call from Coeliac UK, to represent them at a local fundraiser, it shouldn't have come as a surprise. I was asked to attend, as representative of Coeliac UK, a charity event in Hyde, Manchester. A group of people were holding the event in honour of one of its members who, some years ago had bequeathed some money in their will, to be solely used and distributed to local charities. The group between them decided on 20 charities, one of which was Coeliac UK, as there are a couple of members who suffer with coeliac disease.

The evening, in early February, was an opportunity for the charities to attend and formally thank the group for the kind and generous donation. It was an opportunity for me to give a vote of thanks, on behalf of Coeliac UK – who luckily provided a few pointers for content, and to say a little on the work Coeliac UK does and where some of the funds may go to. It finished with photos and a small buffet – with a gluten free offering provided – and an opportunity to talk to others about living without gluten. There was even an opportunity to talk to someone who had a family recently diagnosed with coeliac disease and I was able to point them in the direction of the Coeliac UK website!

Never underestimate the shadow you cast and the impression you make on others. It could take you places you wouldn't have thought to go.

#### Recommendations

In Hornsea, there is **Whiteheads Fish & Chips**, where the team are "honoured, proud and so, so delighted to say we are officially your 2023 UK FISH & CHIP SHOP OF THE YEAR!" <a href="http://whiteheadsfishandchips.com/">http://whiteheadsfishandchips.com/</a> "We offer gluten-free choices for people with food allergies seven days a week." This has been highly recommended by several group members including Hazel and Chris Watson.

The pie-making national chain **Pieminister** has opened a new restaurant in Leeds, where gluten free pies and accompaniments are available.

https://pieminister.co.uk/restaurants/leeds/

15 - 17 Duncan Street, Leeds LS1 6DQ (close to the junction of Briggate and Boar Lane)

The gluten free pies are:

- Gluten free Moo A British beef steak & gluten free craft ale pie
- Gluten free Ranger A free range British chicken & ham pie with leek & thyme
- Gluten free Mooless Moo A jackfruit 'steak', gluten-free craft ale and black pepper pie

You can have several options, including:

- Pie and Two sides £13.00
- Mothership any gluten free pie, mash, garden peas and Cheddar cheese £13.50
   All include a pie and gluten free gravy

They also serve gluten-free Peroni, as well as wines and soft drinks

# **Forthcoming events**

# **Coffee mornings**

Our next coffee mornings are as follows, starting at 10am. We look forward to a coffee and a natter with you. No need to let us know whether you are coming, just turn up.

- Monday June 5th Hungate Reading Hub, Stonebow, York
- Tuesday July 4th York Theatre Royal (including AGM see below)

There is no coffee morning in August

**Please Note:** From September, we shall change the organisation of the coffee mornings. We shall have a monthly coffee morning at the Bar Convent in York, at 10am on the third Saturday of the month. The first one will be on 16<sup>th</sup> September. Chris Elliott would like your feedback on this plan – tel/text 07821 443934 or email <a href="mailto:chriselliott583@qmail.com">chriselliott583@qmail.com</a>

## Children's Event at Agility Outdoor Park on 1st July 12pm

We are now taking bookings for the Ninja Warrior Party at the Agility indoor fitness park which is at Millfield Lane, Poppleton (almost opposite Manor CoE Academy). This consists of one hour (exclusive to us) on the obstacle course and 45 minutes in the party room. They provide a coach who takes the participants through the obstacles. Food is provided in the party room and this will all be gluten-free. Our one hour on the obstacle course starts at 12.15 pm, but all participants must be there by 12 noon for a briefing and for a **waiver form** to be signed. You can complete an online waiver form in advance at <a href="https://bit.ly/3LaGKMS">https://bit.ly/3LaGKMS</a>

The cost is £18.95 per participant, but the Coeliac Group committee has agreed to subsidise this, and we are only asking participants to pay £10 each. Please complete the booking form at the end of this newsletter.

# **AGM**

Under the Coeliac UK rules, we must have an AGM before the end of June or soon after. So we are going to incorporate this year's AGM into our coffee morning at the York Theatre Royal on Tuesday 4th July. We hope you will be able to come along. The agenda for this meeting is on the following page.



# YORK LOCAL GROUP AGENDA FOR THE ANNUAL GENERAL MEETING To be held on TUESDAY, 4<sup>th</sup> <u>July</u>, 2023 AT THE THEATRE ROYAL YORK at 10am

- 1. Apologies for Absence
- 2. Approval of Minutes of last year's meeting held on Sat 10<sup>th</sup> September 2022 and Matters Arising
- 3. Group Organiser's Report
- 4. Treasurer's Report
- 5. Resignations
- 6. Election of Committee and Officers
- 7. Any Other Business

# Booking form for Ninja Warrior Party at Agility Outdoor Park on Saturday 1st July Price £10 per child

I wish to attend this event.

Name:

How many children:

How many are coeliac:

Please send these details to Lynda Moody in one of the following ways:

- By sending this form by post (see address below)
- By emailing Lynda at <a href="mailto:lyndamgf@icloud.com">lyndamgf@icloud.com</a>
- By phoning Lynda at 01904 341866

Please send payment with your booking, see below for ways to do this.

If possible, please also complete an online waiver form in advance at <a href="https://bit.ly/3LaGKMS">https://bit.ly/3LaGKMS</a>

Please could send your payment and booking to Lynda by Friday 16th June

You can pay in either of the following ways:

1. Online via BACS or by going into your Branch and giving them the following BACS details:

Bank Account: Coeliac UK-York

Sort Code 30-94-28

Account No 63201060

quoting Ninja Party as reference

2. Send a cheque made payable to: **Coeliac UK – York** to: Lynda Moody, 13 Sandstock Road, Heworth, York YO31 1HB

We care about your privacy, so we will keep your data secure. You can see our full Privacy Policy at https://www.coeliac.org.uk/privacy-policy/. You can update your personal details and preferences by logging into the Coeliac UK website, by contacting the local group or by phoning the Coeliac UK Helpline