Your
charity
newsletter

CROSSED GRAIN

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coeliac uk

Resilient Rosie inspires mum's marathon

Diagnosed with coeliac disease at just five years old, Kimberley's amazing daughter Rosie is the driving force behind our fundraising hero's mission to take on the London Marathon. We caught up with her between training to find out why she put herself forward for the momentous challenge of running 26 miles.

Kimberly and her daughter Rosie

"I'm a practice nurse yet back when Rosie was diagnosed, I can honestly say that I hadn't fully appreciated the enormity of what coeliac disease would mean to her daily life. She's seven years old now and it's made her grow up quickly. Away from home she's often had to speak up for herself and her gluten free needs, sometimes having to navigate difficult situations to keep herself safe, as well as checking food labels - and those are big asks for a little girl.

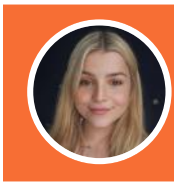
For my part, I got to grips with cross-contamination, shopping and the cost of gluten free food, but that was nothing compared to my amazing daughter, whose daily life would be affected forever. It's Rosie, that's pushed herself forward the most and she gives me motivation for running the marathon.

At the start, the most worrying times with Rosie were when her mental wellbeing was affected. She felt she didn't fit in and had spiralling fears of being cross-contaminated, that stopped her wanting to eat or drink. Fortunately, with the support of brilliant health professionals and the guidance offered by Coeliac UK, we've worked through these challenges.

I hope that by taking up the challenge to run for the charity and raise awareness of what it means to have this serious medical condition; it will help more people. Many of the health professionals we met along the way handed us brilliant information resources from Coeliac UK and I hope that my fundraising will help them continue to provide the valuable support that felt like a reassuring lifeline in our diagnosis journey with Rosie.

I'll be nervous about running the 26.2 miles, but having Rosie and my family cheering me on will fuel my determination and I hope to make them proud. After the marathon, I am looking forward to popping open a mini prosecco to celebrate, followed no doubt by our favourite 'Lasagne Surprise' for supper, which turns out differently every time I make it!"

Thank you, Kimberley, for your incredible support and good luck!



If you'd like to take on a fundraising challenge, contact Amy in our friendly fundraising team or find out more at: **coeliac.org.uk/challenge-events**

You backed these brilliant dietitians

Coeliac UK bursaries help make life better for the gluten free community

The challenges of NHS funding hugely limit ongoing training opportunities for dietitians. It was truly fantastic that thanks to funds raised by you, Coeliac UK could step in and help support 12 dietitians to benefit from the valuable opportunity to join the world's leading coeliac disease specialists - at the 20th International Coeliac Disease Symposium, held at the end of last year.

You made it possible for them to attend this influential conference to access the very latest thinking and scientific knowledge from worldwide medical leaders. Your support also means that they can take valuable learnings and insights back to share with their fellow health professional colleagues for the benefit of the coeliac community.

"The chance to attend such a prestigious international conference was invaluable and not something I would have been able to access without the Coeliac UK bursary. It really was a transformative experience as it provided a rare opportunity to hear from experts around the globe, explore the latest research and advancements in coeliac disease and bring this knowledge back to share with my colleagues. The insights I gained are already influencing our practice, leading to improved care for the patients we serve."

Gastroenterology specialist dietitian, Justice Kofi Amegashie

Great Western Hospitals NHS Foundation Trust, Swindon

Held in the UK for the first time ever, it's unlikely that this international conference will happen again in the UK during the working careers of the most of today's dietetic workforce, which made the opportunity that you helped to support, even more valuable.

What's more, thanks to you, Coeliac UK can support and share expertise with an even wider network of over **1,300 health professionals**.

We do this because no other organisation is producing the expert information or providing the training and resources that these dedicated health professionals need, not just for themselves, but to share with their patients.

2025 Coeliac UK Research Conference

Following last year's event in Sheffield, the next International Coeliac Disease Symposium (ICDS) takes place in 2026 in Melbourne, Australia.

Meanwhile, in June 2025, Coeliac UK will be reconvening the nation's coeliac disease professionals here in the UK, with its own research conference in London. This unparalleled opportunity for those passionate about improving the lives of those with coeliac disease, is expected to attract around **200 healthcare professionals**.

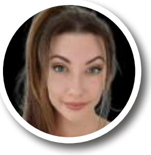
You can watch the highly informative Patient Forum talks from last year's ICDS via our website now at **coeliac.org.uk/icds-patient-forum**

The experts behind the latest research into coeliac disease

We are passionate about advancing research, and thanks to incredible supporters like you, these projects are transforming lives and bringing us closer to a future without coeliac disease.

Dr Mohamed Shiha recently published his paper on the no-biopsy diagnosis of coeliac disease in adults - helping progress discussions that could one day fulfil the goal of a less invasive, and faster diagnosis method.

Imogen Hughes has been researching online Cognitive Behaviour Therapy (CBT) to help patients better cope with the psychological impacts of coeliac disease and the gluten free diet.



Dr Michael FitzPatrick and **Dr Lisa Ciacchi** began studying rogue cells after you helped raise over 80% of the £250k target for this three-year project, last summer.

Visit: **coeliac.org.uk/current-research** for more information about the projects that you're making possible.

Coeliac UK influences global discussions on allergen labelling

You might not have heard of Codex, but what they do, matters to you if you need to live gluten free. The Codex Alimentarius Commission or CAC was jointly created by the Food and Agriculture Organisation (FAO) and the World Health Organisation (WHO) and it's the most important international body in the field of food standards.

Codex may have a complex name, but it plays a crucial role in international food safety debates. Late last year, the international Codex Committee on Food Labelling (CCFL) held its 48th session in Québec City, Canada.

Delegates from 44 member countries, one member organisation (the European Union) and 26 observer organisations, including the Association of European Coeliac Societies (AOECS), attended. At Coeliac UK, we recognised the significance of this event, particularly as key discussions focused on crucial topics like food allergen labelling and the use of precautionary allergen statements (e.g. "may contain"), which directly impact the gluten free community.

As a UK charity, we don't get to have a seat at this global table, but we know how important it is to influence those that do. Because we know how hard it can be shopping gluten free and we believe it shouldn't be such a hassle.

What did we do?

Behind the scenes, long before this key meeting took place, Coeliac UK has been fighting hard. We campaigned to make certain that these international discussions, and the draft guidelines that came out of the meeting, specifically included provisions for coeliac disease and everyone who must live gluten free. This involved working closely with the AOECS, other global societies related to coeliac disease and briefings with the UK Food Standards agency, in advance.

Food and Agriculture Organization of the United Nations | World Health Organization

What changed for the better?

Together, we helped influence two key documents:

1. As part of the general standard for labelling of prepackaged foods, due to the advocacy of our supporters, we were able to get the definition of 'coeliac disease' included, as well as a note allowing for both the cereal (for example 'wheat') and the word 'gluten' to be highlighted in the ingredient list.
2. Within the guidelines for using precaution allergen labelling for prepacked foods, we gained agreement that the guidelines also apply to people with coeliac disease as well as consumers with a food allergy. And we highlighted that wheat protein and gluten are different proteins and need to be considered separately.

What happens next?

Thanks to your support and ready for the next Codex meeting (scheduled to take place in 2026), we'll be working hard to advocate for the best thresholds for the other cereals containing gluten (rye and barley). Codex standards are not a substitute for national legislation; this said, they often form the basis for national laws, which is why it is important we continue to actively contribute to the discussions and drafting of these standards.

We'll keep you updated, as we'll be vigilantly monitoring these areas and wherever relevant contributing with available evidence.

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A gift in your Will could help secure a future free from coeliac disease

Every year we are humbled to learn about our amazing supporters who have chosen to leave a gift in their Will. These special gifts will help transform the future for people with coeliac disease. Many make this decision due to genetic factors, as their family members either have coeliac disease or face a higher risk of developing it.

Roy from Devon chose to leave a gift *"in appreciation of the considerable help afforded to my mother-in-law during her later life"*

March is Free Wills Month, and if you are considering updating or writing your Will, Coeliac UK can help you to do this free of charge. Visit: **coeliac.org.uk/wills** for more information.

Joyce found the process really straightforward:

"We were planning to update our Wills, and contacted one of the local solicitors taking part in the Free Wills scheme. They couldn't have been more helpful, and we were delighted to leave a gift in our new wills to Coeliac UK. They have supported me so much over the years, and our gift will help them to carry on helping other people like me!"

You help friends share gluten free life together

The wonderful support you give helps our volunteers do what they do best – supporting people when they need it – together in their own local community.

Following a gluten free diet can sometimes feel challenging, isolating, and confusing but meeting people with similar experiences at your local Coeliac UK events hosted by wonderful volunteers can make a real difference.

From listening to the stories shared with us, we know that so many people on their gluten free journey, and living with coeliac disease, need and value the support of others who are navigating similar experiences. It can help them feel part of a community and help them understand more about and living well with their condition.

Thanks to your support and because of our enthusiastic volunteers, over 40 regular Meet Ups currently take place, open to anyone across the UK, get together to share experiences and offer a friendly ear. Our community boasts a wealth of knowledge and between them help each other to find and discover more gluten free food and dining options close to where they live. Plus, when they do get together, they feel safe knowing that they won't feel different to anyone else there.

Here's what people have to say about the benefits of coming together at their local Coeliac UK events:

"I did the Coeliac UK volunteer training, which helped me no end when I set up our first event last year. I was motivated to get involved because my son, George was diagnosed at just 17 months and I really wanted to meet other people with similar experiences. We welcomed a fantastic 50 people at our first event, and we also got to meet a family whose daughter has coeliac disease and is a similar age to George. It was heartwarming to hear how so many of the other adults there - some who had been diagnosed for years, said that they felt a real sense of fellowship chatting with others who understood what it means to live gluten free."

Charis, Dumfries & Galloway

"It's so nice being out with a group where I'm not 'special' or even a nuisance. We exchange gossip on places to eat, we exchange recipes and even second-hand cookery books! It's so nice not to have to explain my condition and be with a bunch of friends."

Russ, South Gloucestershire

"In the places where we meet, I'm never the odd one out, or ever feel the need to 'apologise' for my gluten free requirements. In fact, it's funny because when our group has an occasion or event where there's a gluten free buffet, the only downside is having to share the food with everyone there!"

Brachann, Cardiff and East Wales

You're helping us grow our volunteer community, enabling more events in more places across the county, giving more people the opportunity to enjoy the fellowship and support that Russ, Brachann and Charis have found.

Thank you for being a friend. In the last year, your generous support helped:

- over **2,000** people who need to live gluten free be able to meet up in their local communities
- welcome and train **43** new volunteers to join our **250** strong team
- **109** teenagers with coeliac disease to join Coeliac UK's Teen Virtual Clubs
- make over **350** nationwide community events possible

If you're interested in getting involved, please register your interest here: **coeliac.org.uk/volunteer-for-us**

Coeliac Awareness Month 2025: Together, we can change lives

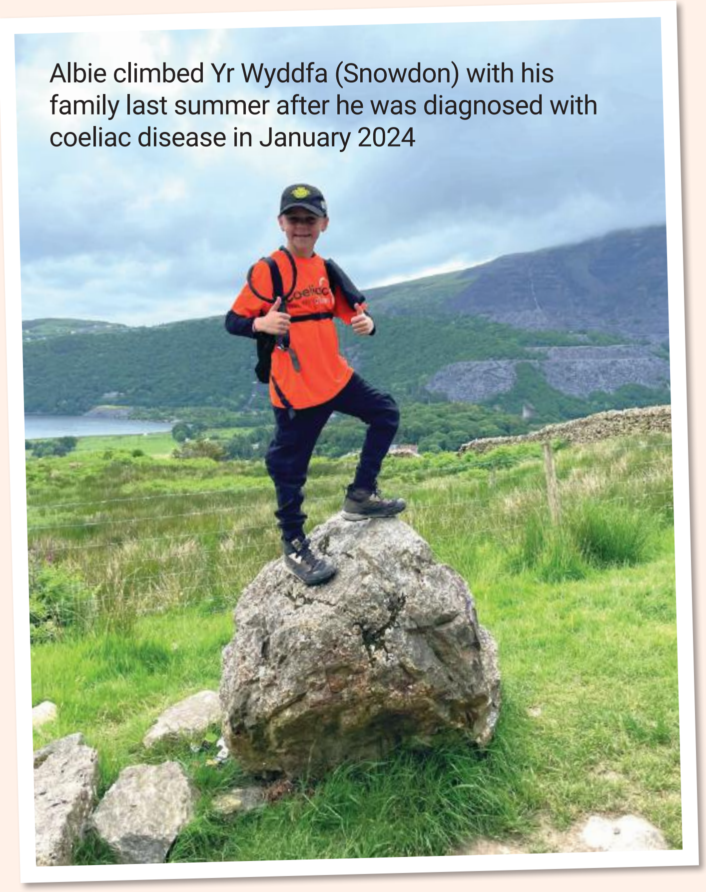
This May, we're dedicating the entire month to spreading the word about coeliac disease and encouraging people to take our online self-assessment and get tested. And you can help!

Every step you take in supporting Coeliac Awareness Month helps us make a real difference for the estimated **500,000** people in the UK still living undiagnosed with coeliac disease.

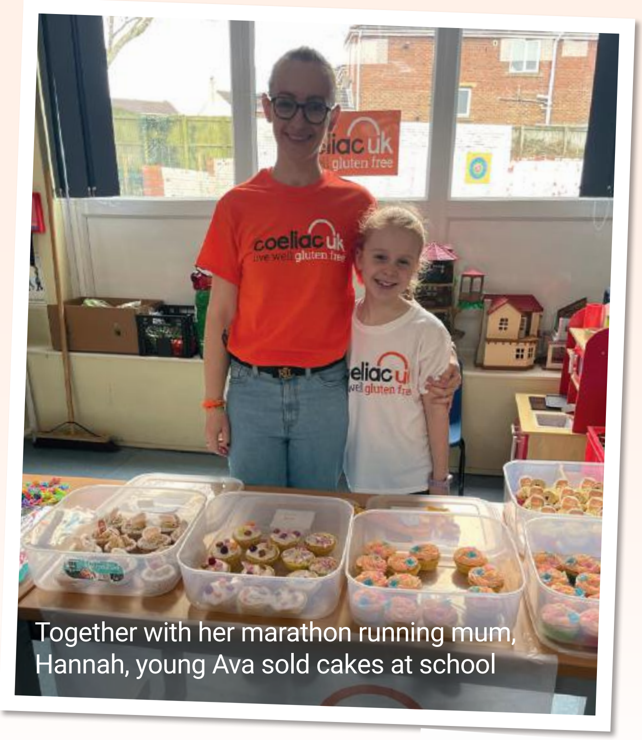
With your incredible support, we can continue providing life changing tools like the '**Is it coeliac disease?**' online self-assessment tool which aims to help people identify whether their symptoms could indicate coeliac disease and if so, help get those people on the road to recovery.

This important resource has already empowered over **320,657** people to take charge of their health by identifying potential symptoms of coeliac disease and guiding them on their path to diagnosis and recovery.

Do you know someone experiencing unexplained symptoms? Encourage them to visit **isitcoeliacdisease.org.uk** and take the online self-assessment to see if they should be tested. It's quick, easy, and could be the first step toward a brighter, healthier future.



Albie climbed Yr Wyddfa (Snowdon) with his family last summer after he was diagnosed with coeliac disease in January 2024



Together with her marathon running mum, Hannah, young Ava sold cakes at school

Fundraise your way and help raise awareness for the 64% of people living with undiagnosed coeliac disease in the UK

1 in 100 people have coeliac disease, but only **36%** of people are diagnosed in the UK, which leaves a staggering **64%** living undiagnosed, often with debilitating symptoms. Using the theme of **64**, join our virtual challenge from **1-31 May** and help us to raise awareness of coeliac disease and raise vital funds for those who need it.

However, much time you have, there's a way to get involved.

Fundraising cousins Pippa and Lilly sewed hair scrunchies to sell to family and friends

Find out more here:
coeliac.org.uk/64challenge
and request a fundraising pack today!

Over 12,500 signatures and counting - thanks to you

With your incredible support, we're on a mission to make gluten free food more affordable and accessible for everyone who needs it.

In November, we launched a petition to protect critical NHS prescription support for those with coeliac disease and we've already reached over **12,500 signatures** which is amazing! This milestone is a direct result of your efforts. Whether you've signed, shared, or championed this cause, we want to say a huge **THANK YOU**. Your voice is making a real difference.

Gluten free staple substitutes are essential for people with coeliac disease to stay healthy, however they're much more expensive and harder to find than their gluten containing counterparts. The NHS has been a lifeline, providing access to gluten free food on prescription, although recent changes to Integrated Care Board (ICB) policies across England are putting this vital support at risk.

Because of your dedication, we've reached a powerful milestone - but the journey isn't over.

Our new goal is to gather even more signatures, amplifying our message and building unstoppable momentum. With your continued support, we'll be delivering this petition directly to **Number 10 Downing Street** in the coming months, demanding Government action to protect this vital lifeline.

If you haven't signed the petition yet, we need you now more than ever. Sign and share the petition with your friends, family, and networks. Every signature gets us one step closer to real change - and none of this is possible without you. Plus, look out for news on our exciting hand in plans.

Sign the petition here:
coeliac.org.uk/prescription-petition

Find out more about our cost of living campaign here:
coeliac.org.uk/availability

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Get in touch

We always love to hear from you, so if you have any feedback or ideas for the next edition of Crossed Grain email us at **publications@coeliac.org.uk**. You can contact us via email **fundraising@coeliac.org.uk**, or by phone between 10am-4pm on weekdays.

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