

# coeliacuk

live well **gluten free**



# Impact Report **2022**





# Welcome

## A note from our CEO, Hilary Croft:

"Maintaining our focus on our beneficiaries and providing high quality knowledge and expertise, has enabled us to continue to deliver positive impact to people affected by coeliac disease throughout 2022. This is despite many challenges we faced with the turbulence in the government and economy.

The Coeliac UK team, pulled together and worked extremely hard to make sure that we did everything we could to stop the external situation making life more difficult for people who need to live without gluten. I'm proud of what we achieved, and I hope you will also be impressed with the impact that we made.

We finished the year with more members than anticipated, in better financial shape than expected and ready to start new research projects in 2023.

As we move into the new year, we are busier than ever. Hopeful, that this year will continue to see us increase our impact - getting more people diagnosed, helping them to have a better quality of life and searching for solutions to help treat and eventually eradicate coeliac disease.

I am so grateful for all the wonderful messages of appreciation for our work, the support we have had, and the donations that have been sent to us. Your support is literally what keeps us going - especially important when times are hard. A heartfelt thank you from me and all the team at Coeliac UK."



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## Research and Advocacy

Funding crucial research to support our ten research priorities is one of our guiding principles as a charity. Ultimately we want a world without coeliac disease and our research priorities are stepping stones to learn more about the nature of gluten and coeliac disease, to lead us to the solution.

## Research

Supported two FSA citizen science projects engaging members of the coeliac community in sharing their experiences of ordering a takeaway and collecting samples for gluten analysis.



## Research Summit

We held our first online research summit with leading experts in coeliac disease and autoimmune research where we explored the evidence gaps for six of our ten research priorities. The outcome of that summit then went on to underpin the criteria for our basic science research call, where we had **£250,000** available to award for one research project.



## Our funded research

Two more of our jointly funded projects with Innovate UK came to an end and reported in 2022. One project has provided greater insight into what is, and what isn't, possible with regard to improving minimally invasive diagnostics for coeliac disease. The other project has determined how a digital application might be useful to monitor patients with coeliac disease, providing reassurance for those doing well and ensuring those who need further support are prioritised and seen in clinic.



## €1.3 million funding for research - finding answers for our community!

We became a collaborator on a project led by Professor Katharina Scherf, supported by other international experts, to explore and improve the analysis of gluten in fermented and hydrolysed gluten free products. The project was awarded an EU grant of **€1.3 million**, it started in the spring of 2022 and will take three years to complete. The objectives of the project include determining if there are better methods of detection for hydrolysed gluten from wheat, rye and barley and to carry out a clinical trial with products containing hydrolysed gluten.

## Research Conference

For the third year, our Research Conference was virtual with nine talks from leading experts. **205** healthcare professional registrations, **1120** video views, **124** certificates issued for continuing professional development.

- > 9 talks
- > 1120 video views
- > 205 registrations





## Advocacy

Our advocacy work was wide ranging. We advocated for the coeliac community as a Member of the Food Standards Agency (FSA) Food Hypersensitivity (FHS) Expert Panel. The panel provides input to the Government's FHS Programme as it has developed an insight into stakeholder priorities and needs. We were also a member and participated in the Great Food Good Health programme which is the NHS's programme for improving food in hospitals, a matter high on our agenda.



## Working internationally to make more of an impact for the coeliac community

In 2022 we reviewed and updated the standard for the European Licensing Scheme for the Crossed Grain trademark.

We attended the International Celiac Disease Symposium in Sorrento and presented a poster with the results of our Clinical Trials and Therapeutics survey. Sharing the views of the UK coeliac community to an international audience. The poster was awarded poster of distinction by the organisers, International Society for the Study of Celiac Disease.



## Representing all nations

We engaged with UK and devolved administrations across England, Scotland, Wales and Northern Ireland to ensure the needs of our gluten free community are met wherever they live, including:

In **Wales**, Rhun ap Iorweth MS/AS (Chair of the Senedd Cross Party Group on Coeliac Disease) tabled a Statement of Opinion, raising the issue of under-diagnosis. It was supported by a further seven Members of the Senedd.

In **Scotland**, Miles Briggs MSP tabled a Motion to Parliament, similarly raising awareness of under-diagnosis. This motion was supported by more than 20 MSPs. In **Westminster**, Jim Shannon MP tabled a question on diagnosis to the Minister for Health and Social care whilst nine MPs tweeted our campaign messages raising awareness to their combined 140,000 followers.

In **Northern Ireland**, whilst parliamentary activity was limited due to the Assembly election, recruitment began for a potential All Party Group for coeliac disease with 15 target MLAs initially contacted. A meeting also took place with the Education Authority regarding the provision of gluten free food in schools.



# Raising Awareness



Raising awareness of coeliac disease and the various symptoms is crucial to increase diagnosis rates and get more people on the road to recovery more quickly. As the world opened up again in 2022 post-COVID we were able to move forward with two major diagnosis and awareness campaigns. The first ran in March and focused on the symptoms to look out for in children, and the second ran in May for Coeliac Awareness Week. Throughout the year we continued to drive awareness through social media, events, PR and our member communications.



Isabelle, Slow Growth



Rocco, Stomach Pain



Lucas, Bloating

## Children's diagnosis campaign

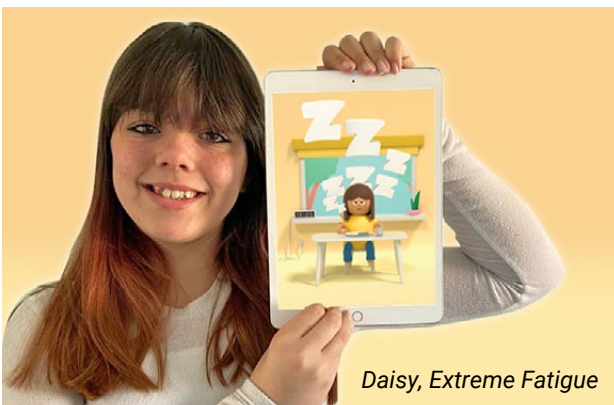
The campaign focused on the specific symptoms to look out for in children and included the creation of animated videos featuring avatars of the children. A huge thank you to Isabelle, Rocco, Daisy, Lucas, and Frankie (and their parents) for sharing their stories!

As part of telling their stories, the children were also keen to reassure others going through the same that it will all be ok.

Daisy experienced extreme fatigue before diagnosis and says: "Before I was diagnosed, I felt that I was stuck forever being sick. That I would never get better. It was horrible. But now, I feel so much better and I'm not tired at all. I can play with all my friends because I am not poorly anymore. I want people with coeliac disease to know that you can always be positive no matter how bad you feel and that once you change your diet things will be so much better!"

"When she was eventually diagnosed with coeliac disease, our lives changed. On a gluten free diet, Daisy is a totally different girl. The bags that were always under eyes are gone, and she's got so much more energy. She's a gymnast now and has even represented Gloucestershire (and won!). We're so proud of her for telling her story to help others."

**Daisy's mum, Helen**



Daisy, Extreme Fatigue

Thanks to our campaign and our community we managed to raise awareness of the symptoms and achieved a whopping



**6.4m social impressions**



Is it coeliac disease?

We drove additional traffic to our diagnosis website pages of **102,294**

And **4,968** people completed our online self-assessment to see if they should be tested.



**93%** of those who completed the self-assessment were recommended to get tested and we look forward to hearing how we can continue to help them through their journey.

You can find out more about the children's campaign and all their stories on our website

[www.coeliac.org.uk/is-it-coeliac-disease/](http://www.coeliac.org.uk/is-it-coeliac-disease/)

# #ShineALightOnCoeliac

1 in 100 people have coeliac disease. Using 100 as your inspiration, take on a challenge and help us raise awareness

## Shining A Light On Coeliac Disease

For Awareness Week (9-15 May) we shone a light on coeliac disease, highlighting the message that **1 in 100** people have coeliac disease, yet only **36%** are diagnosed.

Throughout the week there was lots of activity including a Facebook Live with our Ambassadors Becky Excell and Jane Devonshire, who took on the task of answering **100** questions in **100** minutes; and a live Q&A session with dietitian Cristian Costas - more than **19,500** people watched these live events.

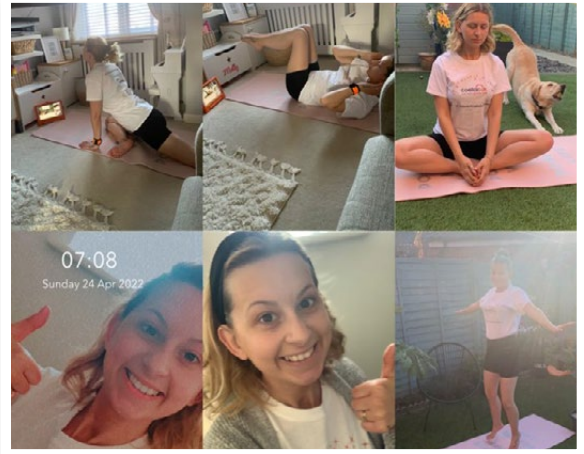


Jane and Becky

We also gained amazing coverage in regional and national press with a PR value of almost **£1.5m**, plus one of our **1 in 100** challengers, 6 year old Etta's 100km cycle ride, was covered on ITV London news. [www.youtube.com/watch?v=jv3BVLYY1Nw](https://www.youtube.com/watch?v=jv3BVLYY1Nw)

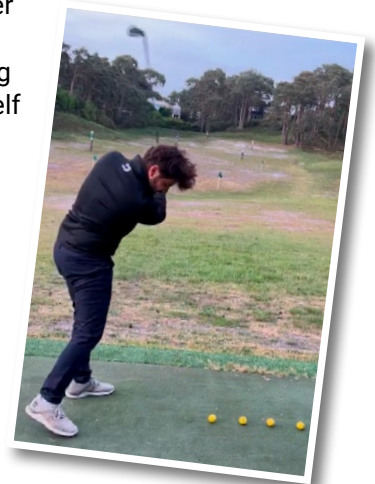


Olivia age 6, made a presentation to her school to raise awareness.



Bethany completed many 'active 100s' and even her dog joined in some of them!

Cookbook author, blogger and keen golfer James Wythe, aka Healthy Living James challenged himself to hit **100** golf balls in **100** seconds and managed to do it!

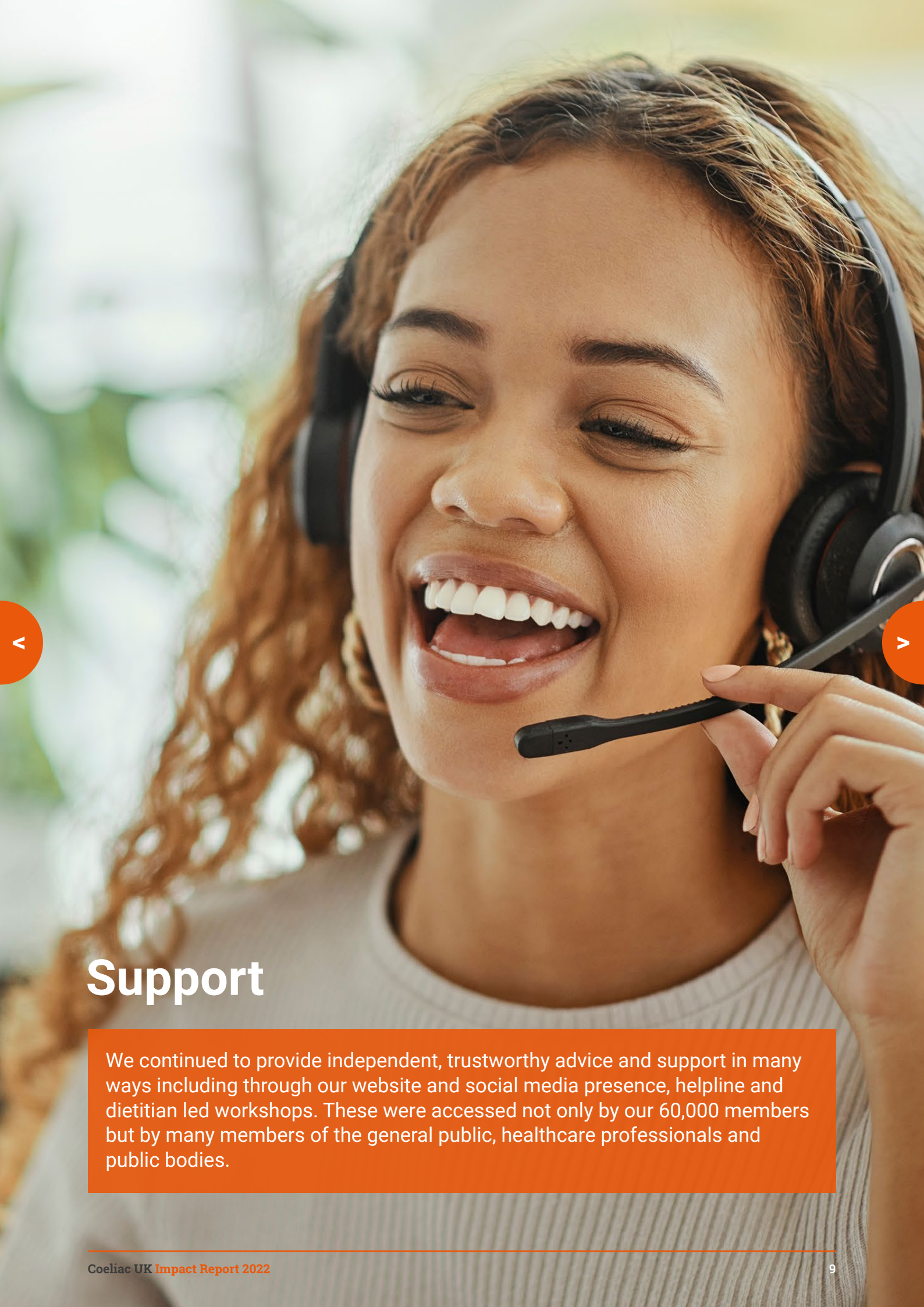


[www.instagram.com/p/CdZDW5MD6xj](https://www.instagram.com/p/CdZDW5MD6xj)

As part of the week **200** amazing supporters signed up to our **#ShineALightOnCoeliac** community challenge raising **£20,000** and **473** people changed their profile picture using our **#ShineALightOnCoeliac** twibbon.







# Support

We continued to provide independent, trustworthy advice and support in many ways including through our website and social media presence, helpline and dietitian led workshops. These were accessed not only by our 60,000 members but by many members of the general public, healthcare professionals and public bodies.



## Practical advice including workshops

“As a newly diagnosed coeliac I found this workshop invaluable. I had already found lots of helpful information on the Coeliac UK website to get me started. This workshop has consolidated that and added further detail. My GP wasn’t really able to give me any practical guidance to manage the disease and I am currently in a long queue to see an NHS dietitian. I am now confident I am doing the right things and can relax about the wait.”

**Annika, Bath**

## Support throughout your journey, from beginner to long term

“This was a really well-presented webinar for those who are just beginning their coeliac journey. It gave a good overview of the challenges that we face and some good practical advice.”

**Neil, Wokingham**

“Fantastic, interactive and informative workshop. Highly recommend to anyone with coeliac disease. Although I have been diagnosed 4 years and have educated myself a lot about the condition, I learnt a surprising number of new facts and information. Never assume you know everything already! Thank you for organising.”

**Joyti, Birmingham**

## Friendly, informative support

“Recently diagnosed with coeliac disease at the age of 75, I was initially daunted by the idea of how to cope, change my diet, and the effect it might have on my husband and family. Joining Coeliac UK gave me invaluable information to help me adjust and this first workshop set out all the essential information about a healthy gluten free diet very clearly indeed. The two dietitians already feel like friends you could happily contact with future questions and concerns. I feel better informed now.”

**Sue, Guildford**



## Support and encouragement on the lonely road to understanding the condition

“After years of illness, we finally have found someone who listens and provides so much information regarding living gluten free, understanding how it feels to be accidentally glutened and what to look for in food and symptoms. All the reassurance, kindness and information makes us so thankful, when others don’t understand the symptoms or the condition. Thank you for giving us the support and encouragement on what can seem a lonely road. The best move we have made is to join Coeliac UK, you are doing an amazing job.”

**Jane, Porthmadog**

## Invaluable services – highly recommended

“Hello, I just wanted to send a message to say thank you very much for all your hard work. Since I was diagnosed with coeliac disease around 10 years ago, I have found your website, food and drink guide and magazine invaluable.



I would highly recommend you to everyone. I’ve found that things have changed a lot in those 10 years - all for the better. Labelling is better, choice is better and people seem to be much more aware of gluten now. Thank you so much.”

**Tricia, Lancashire**

“The app has helped so much when I have been stuck in a supermarket and confused.”

**Claire, Rhondda Cynon Taff**

## 2022 Apps in numbers:



## Championing our volunteers

We're so grateful for the support our volunteers provide to their local communities. With **50** local groups and close to **370** volunteers in a range of roles, supporting our community through virtual meetings, events and providing crucial information and advice.

We're also so thankful for the support our volunteers provide us, our members and their communities. 2022 saw a wide range of local events from expert speakers to children's parties, alongside telephone support through our Member2member scheme, all supporting our community and raising awareness.

**370**  
volunteers

**50**  
local groups



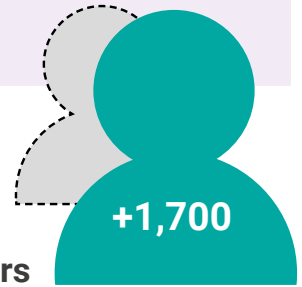
## Helpline in numbers:

We answered **14,028** telephone, email and web enquiries - that's an average of **56** enquiries every working day.



## Our members

We welcomed back **1,700** lapsed members



Overall membership acquisition increased by **2%** and **20%** of members decided to try our digital membership package.

**81%**  
of new members  
are extremely  
satisfied/satisfied

(according to our 9 month satisfaction survey).



**49.53** – Net Promoter Score (members likely to recommend Coeliac UK to a friend or colleague).

'Our diet and health workshops supported over **180** individuals with a range of information to support them at whatever point of their journey:

- Newly diagnosed
- Calcium and iron
- Supporting your child
- Eating out and travelling gluten free

We also delivered a series of free dietitian led webinars especially for local group members to re-engage them with local activities; **106** people benefitted from these sessions.



# Community

Community is at the heart of everything we do. We would not be here without our incredible community of supporters, including the generous gifts of those who have remembered us in their Will.

## Leaving a legacy



*In memory of Dorothy Foster.*

We are very grateful to Dorothy's family for the donation received in her memory, her daughter Gill kindly shared her story and also told us: "It was always her wish that Coeliac UK should be remembered in her and my father's Will, as thanks to the help and support of the charity, she enjoyed a full and active life, playing tennis and fell walking up into her mid-eighties. She lived to the ripe old age of 91, 51 years after her diagnosis!"



We were delighted to see the return of many of our favourite challenge events around the country which Co-op kindly supported. Our super fundraisers ran, walked, cycled and tirelessly fundraised an incredible **£45,000**.

## Just go for it!

"If you are thinking about doing a fundraiser event for Coeliac UK my best advice would be to just put yourself out there and go for it! It doesn't need to be something big or fancy, as the main aim is to share the message about living with coeliac disease and the amazing work of Coeliac UK! If lots of people make small impacts in their local community, the cumulative effect can be amazing!"

**Lucy, Bolton**



## Being part of a community

It's always a wonderful feeling to be part of something bigger, to contribute to something as a team.



*The Connor Family, Surrey.*

## Amazing donations funding research and our crucial services

Our community raised over **£650,000** in many ways including an incredible **£140,000** for the Coeliac UK Research Fund through the Journey to a Cure Appeal.

Hundreds of people took part in the Community Challenge during Coeliac Awareness Week. Plus, a big thank you to everyone who registered for Gift Aid as this allowed us to claim an additional **£129,000**.

Our Summer and Christmas Raffles raised **£218,000** including **£38,000** in donations.



James, the son of Craig who won a gluten free hamper in the Christmas Raffle

“After a really tough year with our son James’s diagnosis it was brilliant to hear we had won a Christmas hamper, it really gave us all a much needed boost. Many thanks to the Co-op and Coeliac UK.”

**Craig, Sheffield**

Pablo,  
**£1,000**  
winner



The Gluten Free Lottery raised **£245,000** for the year, meaning funds via the Lottery topped **£1million** in total since it started in 2017. A big thank you to everyone who plays every week!

## Leaving a legacy of support

**£762,000 received** through Legacies and Wills.

We are very grateful to everyone that remembers us through Legacies and Wills. Not only does this make a lasting difference to the lives of people with coeliac disease but it also means that our supporters can leave a positive and life changing legacy.

## Merchandise through our shop helps support our work

Our shop stocks a range of items to help our community live well gluten free, including cookery books to useful branded merchandise like toaster bags, ‘gluten free only’ fridge magnets and of course our annual selection of Christmas cards which saw sales of **4,000** in 2022! All proceeds from Shop sales come back to Coeliac UK to support us in our work.



## Promoting access to safe gluten free food

Our focus remains firmly on ensuring that our community has access to safe gluten free food, and in 2022 we continued to work with catering and brand partners to promote and develop our food safety schemes. Our Crossed Grain trademark is the number one symbol for gluten free food safety. For packaged products it provides reassurance to consumers that the product is safe and is hugely welcomed by brands:

“The Crossed Grain trademark is really useful to us as a brand. It gives consumers peace of mind that our products and production methods have passed certain checks. Allowing them to make a confident decision when picking up our products!”



Alistair Dunn,  
Brand Manager,  
The White Rabbit  
Pizza Company

Knowing where you can eat out safely is essential for people with coeliac disease and when they see our Gluten Free accreditation logo, they know that the venue has processes in place and staff trained to cater safely for their needs.

## PREZZO

“Prezzo is proud of our Gluten Free accreditation from Coeliac UK. We’re delighted to offer our customers a variety of over 40 gluten free dishes throughout our adult and kids’ menu. Working with Coeliac UK gives our customers the reassurance that all strict standards are adhered to. Our restaurant teams are fully trained and confident in cooking and serving our delicious gluten free dishes. It means more people can experience the joy of Italian dining at Prezzo.”

Hannah Thompson, Marketing Director, Prezzo

Understandably, the pandemic had a major effect on the catering industry, but we have been heartened to see an uptick in trade to venues - and renewals; new enquiries and audits returning to normal for our Gluten Free Accreditation Scheme.

## New partnerships for 2022 and beyond

We are delighted to welcome Panasonic as our sponsoring partner for the Home of Gluten Free recipes, and White Rabbit as our Gold Sponsor of the Food Information Service.



90% of Crossed Grain partners renewed in 2022



Over 3,000 venues now awarded our GF accreditation

## Helping Ukraine

When we heard the news about the situation in Ukraine, we wanted to do as much as we could to provide support quickly.

We asked our community to help us raise funds and have matched all donations to a total value of **£14,000**. These funds, plus those gathered by our partners within the Association of European Coeliac Societies (AOECS) are being used to provide assistance of food and support to people with coeliac disease inside Ukraine and refugees in neighbouring countries.

# Financial summary

## 2022

Income: £4,054,439

Expenditure: £3,515,612

## 2021

Income: £3,584,922

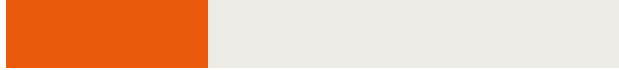
Expenditure: £3,391,079

### Proportion of spend

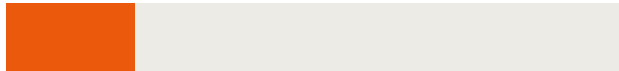
Raising awareness 42%



Support 33%



Community 21%

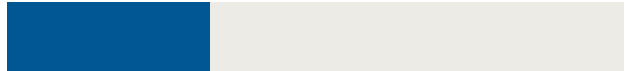


Research 4%

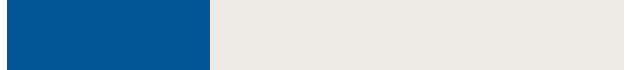


### Proportion of spend

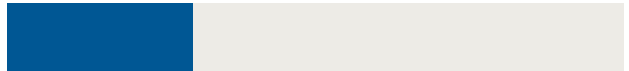
Raising awareness 33%



Support 33%



Community 30%



Research 4%



You can read a full statement of Coeliac UK's 2022 Consolidated Accounts at [www.coeliac.org.uk/plansandreports](http://www.coeliac.org.uk/plansandreports)

## Thank you

2022 was a year of many challenges and we achieved what we did thanks to our amazing community including our members, fundraisers, online supporters, commercial partners, healthcare professionals, research teams and of course our committed and tenacious volunteers and staff.

We look forward to a successful 2023 and thank you for your continued support. Together we can make a difference – visit [www.coeliac.org.uk/get-involved](http://www.coeliac.org.uk/get-involved) to find out how you can get involved.



[www.coeliac.org.uk](http://www.coeliac.org.uk)



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