

coeliacuk

live well **gluten free**



Impact Report 2021





Introduction

A note from our CEO, Hilary Croft:

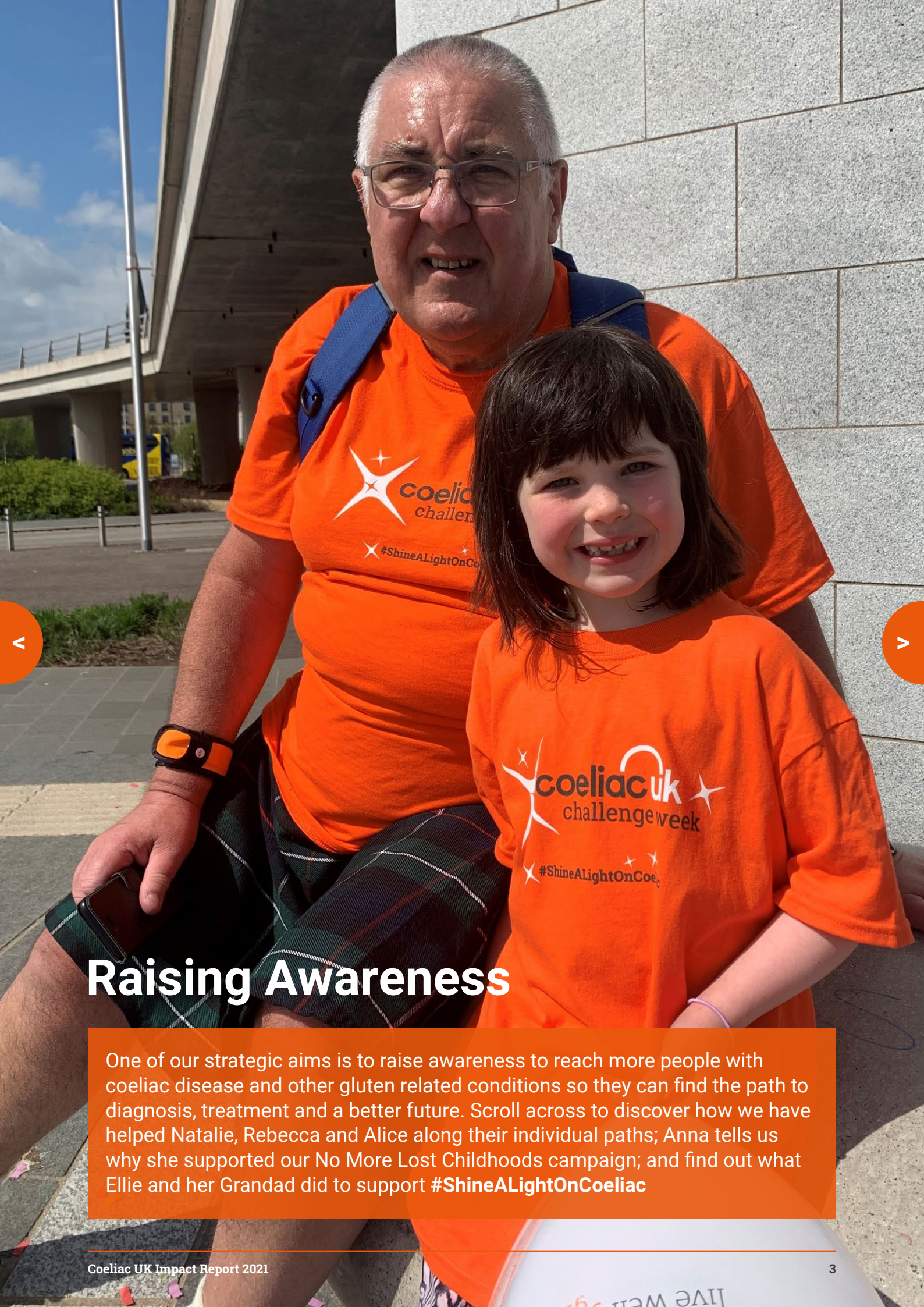
“People are always at the heart of what we do, whether it’s research to help us develop new approaches, the creation of inspiring recipes to make living well gluten free a pleasure, or even just being there, through support services such as our helpline. To reflect this, our 2021 Impact Report focusses on a number of personal stories that illustrate how we’ve positively impacted the lives of so many of our community. We are proud of what we do to make a positive difference in people’s lives.

2021 began with a reminder that the pandemic was far from over meaning our plans to get out and support our community face to face had to be revised and delivered virtually. Thankfully the unwavering support of our community and our ever flexible staff saw us finish the year on a positive note and with many good outcomes, and I’d like to personally thank all of those responsible for making this happen.

To reflect our strategic objectives the Report is separated into sections that define our core missions: Raising Awareness; Support; Community and Research. I hope you enjoy reading it, and as always, we are here if you want to discuss any aspect of our work or how you can get involved to help us achieve our goals.”



“People are always at the heart of what we do. We are proud of what we do to make a positive difference in people’s lives.”



Raising Awareness

One of our strategic aims is to raise awareness to reach more people with coeliac disease and other gluten related conditions so they can find the path to diagnosis, treatment and a better future. Scroll across to discover how we have helped Natalie, Rebecca and Alice along their individual paths; Anna tells us why she supported our No More Lost Childhoods campaign; and find out what Ellie and her Grandad did to support **#ShineALightOnCoeliac**



Tools to help others understand

“Coeliac UK have enabled me to direct myself through my first year of coeliac disease and being gluten free. They helped me to make safe food choices at home and out and about and gave me the tools to ensure others are educated about coeliac disease when cooking for me.”

Natalie, Woodley



Finding answers

“After living 30 years of my life undiagnosed, I had no idea where to start. I was anxious and confused. Coeliac UK have made me feel as though I’m not alone with coeliac disease and the resources have helped me to understand my condition. I am now confident in managing my condition and living my life to the fullest while looking after my health.”

Rebecca, Nottingham



Sharing information

“Diagnosed during a pandemic, the website and app were the places that gave me the information I needed. I felt hopeful instead of deprived. I have used the website to share information with family and friends. The app helps me feel more confident about the foods I can buy.”

Alice, Chorley



Supporting our No More Lost Childhoods campaign

Anna shared her moving coeliac disease diagnosis story with us to support our No More Lost Childhoods campaign.

“The overriding memory I have of my childhood is that I felt ill. I wasn’t diagnosed until I was 25. I supported the campaign because I want the anger and passion I feel today to stop other children from having to experience the same.”

Anna, Rugby

#ShineALightOnCoeliac

Shining A Light On Coeliac Disease

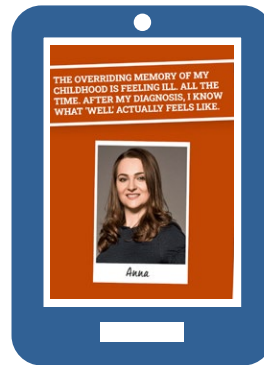
For Awareness Week we shone a light on coeliac disease, to help children and young people feel more confident about living gluten free. As part of the week 200 amazing supporters signed up to our #ShineALightOnCoeliac community challenge raising **£50,000**. The week gained 5.5m social media impressions; 3,457 pieces of national, regional and trade press, the equivalent of **£3.9m** PR value.

Six year old Ellie, who has coeliac disease, and her Grandad stepped up to the challenge to shine a light on coeliac disease for Awareness Week. Together they walked the 2.5 miles across the Tay Bridge. Ellie raised a fabulous **£1,310** for Coeliac UK and featured in local press.



Paving the way to diagnosis

For the first time in almost two years, our Evidence and Policy team met face to face with GPs when they attended the Royal College of General Practitioners (RCGP) Annual Conference. Attended by over **1,000** GPs it is a great opportunity to increase awareness about coeliac disease, diagnosis and management.



28,808
online assessments
were completed via

isitcoeliacdisease.org.uk



4 million
unique page views

1.3 million
website users/visitors



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 62,000 members but by many members of the general public, healthcare professionals and public bodies.



Coeliac UK - my only source of information

“Coeliac UK have been an absolutely invaluable wealth of information to me. When I was diagnosed, they were my only source of information for some months before I got an appointment with a gastroenterologist. Coeliac UK helped me to understand coeliac disease and the gluten free diet a lot better. I’ve shared resources with family members to help them better understand. The staff on the phone lines are always there for any questions.”

Holly, Manchester

Apps make finding gluten free food easy

“The apps have helped me massively in identifying what is gluten free and not, and being able to search for gluten free accredited restaurants has taken the pressure off eating out.”

Ryan, West Midlands

Value of membership

“Whether you are newly diagnosed or have had the condition for some time, joining Coeliac UK is a valuable, informative and reliable source of information to help you to live with coeliac disease well.”

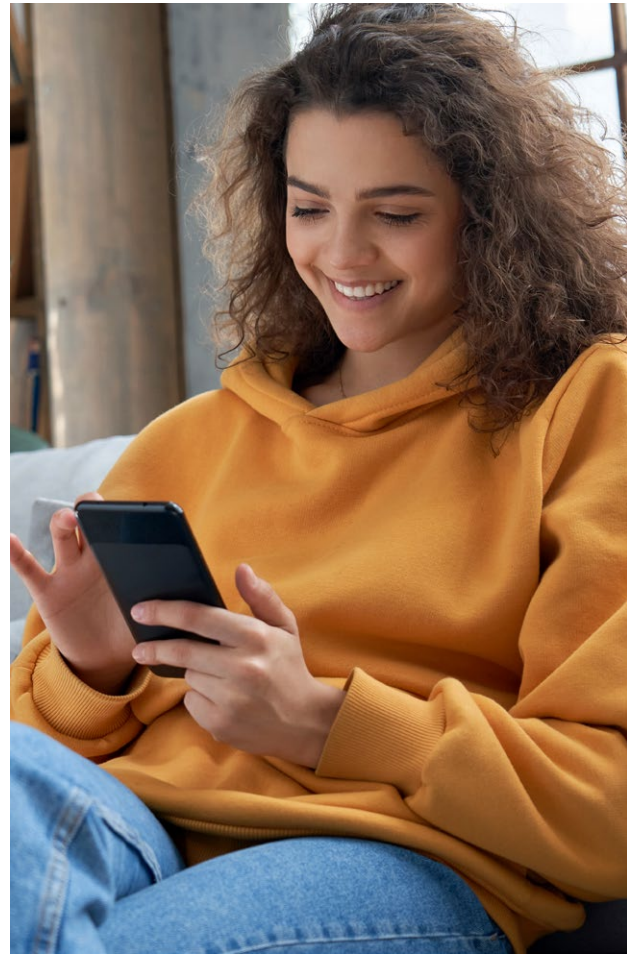
Andrew, Ely



Always there to help

“Coeliac UK has helped me feel like I’m not alone and that there are plenty of recipes and information about coeliac disease out there.”

Harry, Hertfordshire



Amazing Recipe

“I have just been spoilt rotten with a plate of delicious homemade scones by my 11 year old daughter. Thanks for the amazing recipe and suggestion.”

Catherine, Sevenoaks

Giving Back

John, one of our Coeliac UK Raffle winners, says “The advice that Coeliac UK gave me, and practical products like the Gluten Free Food Checker app, enable me to maintain a healthy gluten free diet, feel better and live an active and healthy life. I now support their work so that more people can benefit from the vital services they provide.”



We've got you because we get you

"I turned to Coeliac UK for guidance and information, throughout the diagnostic process when I needed reassurance, and ever since I've been learning to eat gluten free, Coeliac UK has had my back! I've looked things up on the website, I've downloaded and used the Gluten Free Food Checker app, I've joined my local Coeliac UK committee, I've rung up to ask for guidance and so much more. It's been a year since diagnosis and I wouldn't have made it this far without Coeliac UK."

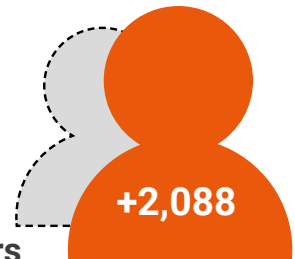
Clare, Basingstoke

2021 Apps in numbers:



Our members

We welcomed back
2,088 lapsed members



Our new digital membership recruitment campaigns supported our **6%** increase in membership retention rates on 2020

17% of members decided to try our digital membership package, launched in November 2019

81% of new members are extremely satisfied/satisfied (according to our 9 month satisfaction survey)



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

Our diet health workshops supported close to **100** individuals with a range of information on: Calcium and iron; Supporting your child; Newly diagnosed; Eating out and Travelling gluten free.

Championing our volunteers

We're so grateful for the support our volunteers provide to their local communities. With **56** local groups and **553** volunteers in a range of roles, supporting our community through virtual meetings, events and information provision.



553
volunteers

56
local groups

Helpline in numbers:

We answered **18,996** telephone, email and web enquiries (that's an average of **70** enquiries every working day).



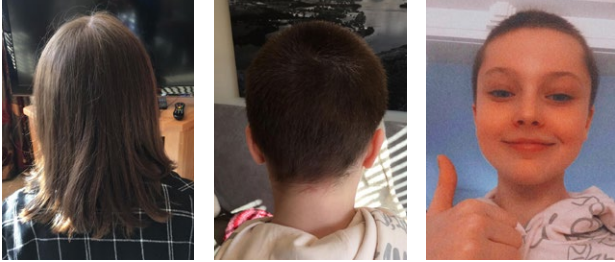
Community

With the ongoing pandemic we weren't always able to meet up with friends and family, but we stayed connected through social media, online events, fundraising challenges and volunteer support. Here are some of the creative ways our community have used to get involved and raise funds.



A close shave!

Maddie (11) raised an amazing **£450** for Coeliac UK by shaving her head. Her mum Lisa says “She wanted to do something different, to give back to the charity that supported her when first diagnosed, to raise awareness of the condition, and to show other children who may have only just had a diagnosis that they can live a healthy life.”



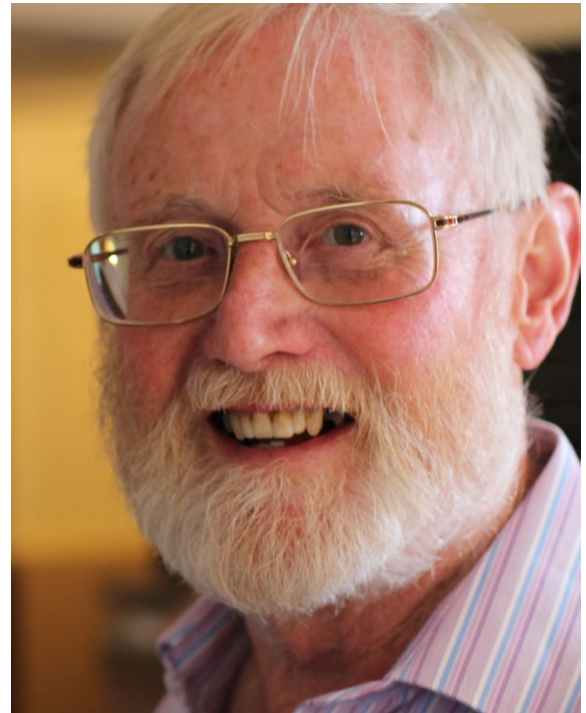
Cookie bake off

Belle was diagnosed with coeliac disease when just 21 months old. As a happy and healthy 10 year old, she wanted to give something back to Coeliac UK. She did a cookie bake off and sold cookies to friends and family.



Leaving a lasting legacy

Brian’s family asked for donations to Coeliac UK in honour of Brian, who was diagnosed with coeliac disease in 1995 and had been a member of his local Coeliac UK group.



Getting involved virtually

Nicky has two daughters with coeliac disease and she took on the Bath virtual 10k to increase awareness. She raised just over **£300** to help support to continue and one day find a cure.



Nicky says:
“Fundraising
is a great way
of profiling the
charity. Do it!”

In Memory

Both Martin, and his wife Karen were diagnosed with coeliac disease and were uniquely able to support each other. Karen sadly died in 2021, but together they supported the coeliac community.



In 2012 Martin raised nearly **£3,000** for Coeliac UK when he ran in the London Marathon.

Our community donated over **£500,000** in many different ways including raising an incredible **£95,000** to support children and young people affected by coeliac disease through our **#ShineALightOnCoeliac** community challenge and No More Lost Childhoods appeal.

Our Spring and Christmas Raffles raised **£230,000** including **£36,000** in donations.



The Gluten Free Lottery raised **£250,000**. **£200,000** received through Legacies and Wills.



We are also grateful to the trusts and foundations who donated to our charity during 2021, including the James Tudor Foundation who gave a grant of **£10,600**, and for the support of the Co-op, working in partnership with us on our Challenge events.

Promoting access to safe gluten free food

During the continuing pandemic with its additional restrictions, we continued to work with our corporate community including restaurant and catering partners in the Gluten Free accreditation scheme and product brands with Crossed Grain licensees.

“Working with Coeliac UK to achieve their Gluten Free accreditation has not only helped reassure people with coeliac disease that our gluten free food is suitable to eat, but also raised awareness with staff and visitors.”

Stuart Donald, Catering Manager, Aberdeen Royal Infirmary, the first hospital in Scotland to gain Coeliac UK's GF accreditation

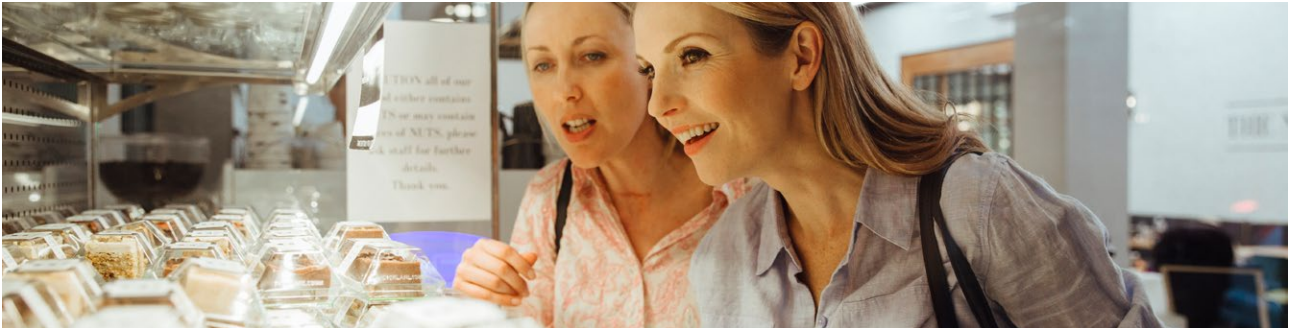


Aberdeen Royal Infirmary Catering Team

“As long-term partners of Coeliac UK, we are proud to display the Crossed Grain trademark on all our gluten free packaging. This provides added and instantly recognisable reassurance to those that need it that our products are of a high quality and certified safe to eat.”

Emma Heath, Head of Marketing, Nairns





Catering establishments were some of the hardest hit in the pandemic, and as our gluten free accreditation has a strong community benefit we were delighted that **90%** of our partners had renewed.



Help on the go

"I joined Coeliac UK because my son, Will, was diagnosed when he was 12. He's now 17. The Gluten Free on the Move app is such a good app when we go on holiday. I wish more independent restaurants and cafes knew about being accredited. They'd gain the business of a lot of grateful GF customers!"

Amanda, Tring



90% of Crossed Grain partners renewed in 2021

Over **2,600** venues now awarded our GF accreditation



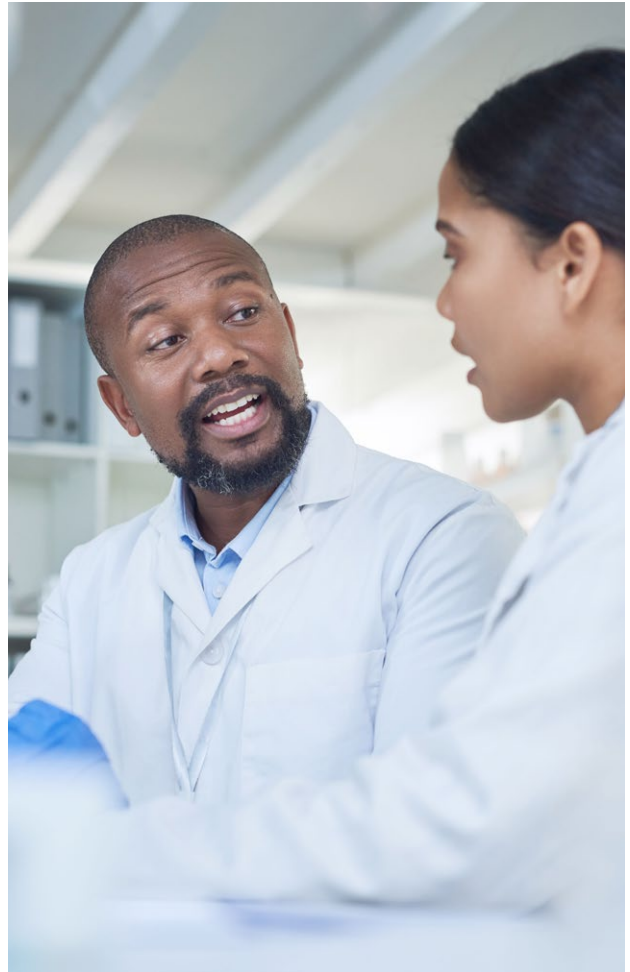
Research

We continued to fund and share crucial research in support of our **ten research priorities**, helping us to learn more about the nature and effects of gluten and coeliac disease.

New initiatives and partnerships

In July we became an associate member of the Connect Immune Research initiative which brings together researchers from type 1 diabetes charity JDRF, the MS Society, Versus Arthritis, Alopecia UK, the Psoriasis and Psoriatic Arthritis Alliance, and supporting partner the British Society for Immunology.

This is a first-of-its-kind charity research partnership to uncover the common threads in our collective work on autoimmune conditions – meaning greater efficiency and hopefully new treatments, faster.



Joint research call

The first of four projects we jointly funded from our research call with Innovate UK, completed at the end of 2021:

Better gluten free bread with new improved ingredients. Dr Lydia Campbell, Nandi Proteins Ltd, other industry partners and Heriot Watt University. Researchers have demonstrated that by exchanging certain ingredients, the quality of gluten free bread may be improved and potentially costs may be reduced.



Dr Lydia Campbell



Improving communication

In August we published our first **Research Fund Impact Report**, which reflected on our research achievements since its launch in 2018.



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 were met wherever they live, including:

- Advertorial in Holyrood magazine focusing on the challenges of diagnosis in Scotland. Holyrood is read by around 3,000 policy makers. We also wrote directly to more than 60 MSPs about the issue.
- Worked closely with Hywel Dda University Health Board, in Wales, as it rolled out a voluntary scheme providing a subsidy to people with a coeliac disease diagnosis to access gluten free staples through shops.
- Re-established the Parliamentary Cross Party Group in Wales and hosted three meetings through the year.
- Wrote to the Northern Ireland Minister of Health and Chair of the Northern Ireland Assembly's Health Committee to raise awareness of the challenge of diagnosis and submitted a joint response with partners to a consultation on the future of the health service in Northern Ireland.
- Met with Westminster Parliamentarians and a Junior Minister to discuss policy initiatives to improve diagnosis of coeliac disease across England.
- Wrote to the Secretary of State for Digital, Culture, Media and Sport regarding the depiction of coeliac disease on the BBC.

Scottish Parliament



Senedd Cymru/
Welsh Parliament



Northern
Ireland
Assembly



Palace of Westminster



World leaders – supporting people affected by coeliac disease

We continued to work with the Association of European Coeliac Societies (AOECS) to support its members and extend and improve gluten free food safety across Europe. We also worked with the International Society for the study of Celiac Disease (ISSCD) to improve outcomes for the coeliac community.

Research Conference

For the second year, our Research Conference was virtual with **10** talks from leading experts. **222** healthcare professional registrations, **1370** video views.

10 leading experts

1370 video views

222 registrations



Financial summary

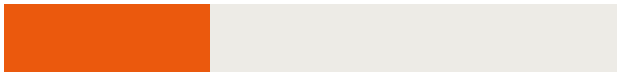
2021

Income: £3,584,922

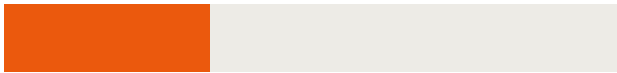
Expenditure: £3,391,079

Proportion of spend:

Raising awareness 33%



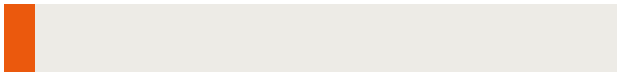
Support 33%



Community 30%



Research 4%



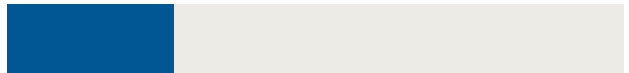
2020

Income: £3,606,652

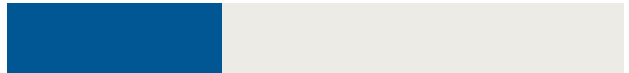
Expenditure: £3,381,417

Proportion of spend:

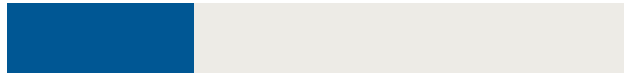
Raising awareness 27%



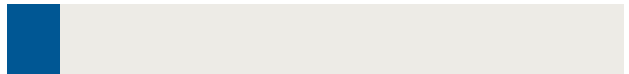
Support 34%



Community 30%



Research 8%



You can read a full statement of Coeliac UK's 2021 Consolidated Accounts at www.coeliac.org.uk/plansandreports.

Thank You

A big thank you to everyone for supporting us in 2021, from our members, fundraisers and followers, to our commercial partners, healthcare professionals and research teams. We couldn't achieve so much without the help of our wider community and look forward to continued support in 2022.

There's lots of ways to get involved with Coeliac UK and everyone can make a difference – visit www.coeliac.org.uk/get_involved to find out more.



www.coeliac.org.uk



Coeliac UK is a charity registered in England and Wales (1048167) and in Scotland (SC039804) and a company limited by guarantee in England and Wales (3068044)