

## **Impact Report 2020**









### Introduction

#### A note from our CEO, Hilary Croft:

Welcome to our Impact Report 2020. I want to take the opportunity to thank you for your support throughout the year and for being an important part of our community.

No one could have anticipated the challenges 2020 would bring – but I've been so impressed by how we have come together to support, care and guide each other.

Not only have my colleagues at Coeliac UK worked tirelessly to interpret Government guidance and develop new services in response to the pandemic – you, our members and supporters have also stuck by us, and given your time, donations and encouragement when we needed it more than ever.

It's not been business as usual – not even close – but we have remained a constant for each other and that is my highlight of a most challenging, busy year. It's because of you we will remain here for everyone that needs to live gluten free in 2021 and beyond.



"I've been so impressed by how we have come together to support, care and guide each other."



## Highlights of 2020



#### 21,141 enquiries

We answered **21,141** telephone, email and web enquiries (that's an average of **81** enquiries every working day).

81 enquiries every working day on average







# Over 150,000 products listed on our Food Information Service

Including almost 4,000 Crossed Grain trademarked products, making shopping for gluten free food easier than ever. What's more, 46 new venues joined our GF Accreditation scheme.



## We reached 135,000 followers across social media

On social media, we received **39,000** messages and comments, and our community grew by **10%**, whilst our website was used to complete **12%** more unique searches for information.



### Raising nearly £1 million

Meanwhile, you helped us raise nearly £1 million (excluding raffles and lotteries) and covered a whopping 3,250km during our Challenge Weekend - you can see some of the amazing photos you shared on the cover!



## Financial summary

2020

2019

Income £3,606,652 Expenditure £3,381,417

Net gains/(losses) (£171,844) Net income/expenditure £53,391

#### Proportion of spend:

Raising awareness	<b>27</b> %
Support	34%
Community	30%
Research	8%

Income £3,840,965 Expenditure £4,033,050

Net gains/(losses) £71,452 Net income/expenditure (£120,633)

#### Proportion of spend:

Raising awareness	<b>27</b> %
Support	28%
Community	31%
Research	14%



Like many charities, we tightened our belts in 2020. Whilst much of our planned research activity was paused, spending on support increased as we developed new services, information and resources to meet your growing needs in this area.

You can read a full statement of Coeliac UK's consolidated accounts for 2020 online at www.coeliac.org.uk/plansandreports.



Early 2020 marked the beginning of a year of uncertainty and change, but also of community, kindness and resilience.

Almost every area of our lives has been affected, from the way we work to how we travel, shop and socialise – but you can still find impartial, expert advice on coeliac disease and living gluten free from Coeliac UK.

Mobilising our contacts across Government, healthcare, research and the food industry, we've done our best to ensure we provide reliable, informed and up to date coronavirus information for our community.

We can't predict how coronavirus will affect our lives in 2021, but we can be sure that no one has to face it alone.



#### Thank you

None of this would be possible without our gluten free community.

Turn to page 11 for a gallery of our member and supporter highlights, and to find out how you can continue to support us in 2021.

#### Responding to a crisis

Here's how we responded to support you in the early months of the pandemic:



- With the support of our **Health Advisory Council**, we released an initial statement, asking our community to follow Government guidance.



- Helpline and social media enquiries increased 500% as our community tried to understand what evolving Government guidance meant for people with coeliac disease.
- Responding to this, we launched our Coronavirus Hub to answer your frequently asked questions, help you find gluten free food, and keep our community connected.
- Meanwhile restaurants, cafes and pubs adapted to takeaway service, and we produced guidance for GF accredited venues to keep food safety front of mind.



- With panic buying creating a shortage of gluten free food in supermarkets, we took to social media to raise awareness and survey its effects.
- We passed the results to DEFRA\*, BRC\*\* and major retailers who we'd been in contact with early on – asking them to protect gluten free food.
- As Government guidance evolved, we sought clarity on whether
  people with coeliac disease were classed as clinically vulnerable
  from Public Health England and the Department of Health an issue
  many of you had contacted us about.
- Facing lockdown for the foreseeable future, we extended volunteer support to those most vulnerable, and continued to offer alternative fee options for those affected financially.
- \* Department for Environment, Food and Rural Affairs \*\*British Retail Consortium



We continued to raise awareness of coeliac disease and other gluten related conditions, and campaigned to protect the availability of gluten free food during panic buying.

#### Paving the way to diagnosis

Although our diagnosis campaign was postponed, **27,392 online assessments** were completed via **isitcoeliac.org.uk** – placing more people on the path to diagnosis, treatment and a better future.

We also helped promote the British Society of Gastroenterology interim guideline

- which introduced a no biopsy approach to diagnosis for some adults, enabling diagnosis when access to elective endoscopy was restricted.



### 27,392 online assessments taken

#### **Providing information you can trust**

When health services were overwhelmed, our website provided impartial, expert advice on the symptoms, diagnosis and treatment of coeliac disease to **1.7 million unique visitors**. Unique searches for information increased by **12%**, whilst our bounce rate (the number of people leaving our website without visiting other pages) reduced by **13.8%**, suggesting it was easier to access the content you were looking for.

1.7 million unique visitors

12% increase in unique searches





"The practical help and advice we get for our granddaughter is amazing. Thank you!"

**Simon Pannett** 

## Making sure everyone's included

Our Tales From a Gluten Free Christmas campaign highlighted the challenges faced by our gluten free community at Christmas time. We shared real life stories for



shared real life stories from our community and provided practical resources via our online Christmas Market to help family, friends and food businesses to safely cater gluten free.



"Coeliac UK is a fantastic help and I get very excited to find out about new products each Christmas."

**Steph Ricketts** 

Our Christmas campaign reached almost 1 million people via social media, with 42,758 unique views of our online Christmas market

### Promoting choice and protecting availability

In response to panic buying, we mobilised our networks to ensure gluten free food was available for those who really needed it.

In April, we launched a social media appeal to raise awareness of the impact of panic buying and conducted a survey to find out how the pandemic was affecting access to gluten free food in the community, which received over **3,200** responses.

The results were shared with the Department for Environment, Food and Rural Affairs, the British Retail Consortium, and major retailers.

We continued to work closely with our partners in the food industry, including 205 licensees with almost 4,000 Crossed Grain trademarked products.



"Well done on keeping the show running despite this year's challenges. And thank you for directing us to crucial alternative suppliers."

**Keith Moor** 





70% had to visit more than one store to complete their food shopping

Of those who received an emergency food parcel, 29% found it contained items unsuitable for a gluten free diet



As we moved to working from home, we continued to provide independent, impartial advice and support to **64,000 members** as well as the general public, healthcare professionals and public bodies.

#### Finding the right answers

We worked tirelessly to answer your questions, interpreting Government coronavirus guidance for people with coeliac disease and helping improve access to gluten free food. Helpline calls and social media enquiries increased by **500**% in March, and in response, we launched our online Coronavirus Hub.

We also developed a new digital resource to support those recently diagnosed and unable to see a dietitian, with useful videos on coeliac disease, the gluten free diet, reading food labels and cooking and eating out. These were shared with Healthcare Professionals too, to help them support patients remotely.





#### **Helpline in numbers:**

We answered 21,141 telephone, email and web enquiries.
That's an average of 81 enquiries every working day!

"I found your covid-19 FAQs helpful and reassuring - thank you!"

**JG Cook** 

#### Improving our services

We continued to improve our current services and identify new areas of need. Our Gluten Free on the Move app won the memcom award for the Best Use of an App, and 12% of members decided to try our new digital membership package (launched in November 2019).

We successfully piloted our virtual Diet and Health Workshops, which will continue in 2021. These are developed and hosted by our expert dietitians to help you meet your nutritional needs.



We welcomed back 2,100 previously lapsed members



90% of new members are extremely satisfied/satisfied (according to our 9 month satisfaction survey)



#### 65.3 - Net Promoter Score

(members likely to recommend Coeliac UK to a friend or colleague)

"Since being diagnosed a year and a half ago, I've turned to you countless times, not only to ease my worries, but to find all sorts of inspiration for making the most of gluten free life!"

**Lara Squire** 

"I found the Helpline really helpful during the pandemic. The person who took my call was helpful and professional, and the information she gave me helped me to decide what I needed to do to keep myself safe."

Marianne



1 memcom award

**Gluten Free Food Checker: 44,200** users (6% increase)

Gluten Free on the Move: 16,600 users (33% increase)

#### Lending a hand

We continued to offer alternative fee options. including the waiving of fees if appropriate, to anyone in our membership community facing financial difficulties on a case by case basis.





Whilst we couldn't always see our friends and family in person, we stayed connected via social media, online events, fundraising challenges and volunteer support.

#### Keeping us connected

As many of us looked for new ways to stay in touch, over **12,000 new followers** joined our social media community. Alongside enquiries to the Helpline, we received over **39,000** messages and comments on social media – an increase of **21**% on 2019.





#### **Celebrating our community**

With our diagnosis campaign on hold, we launched Gluten Free Community Week. It was packed full of interactive online activities to help our community stay connected whilst raising urgent funds for Coeliac UK.

#### In the news:

203 pieces of online and print media coverage with a readership of 39 million



10% more social media followers by the end of 2020



Ambassador and MasterChef Champion Jane Devonshire kick started Gluten Free Community Week with a virtual bake along, which was viewed almost 9,000 times.

Trending topics: #gfCommunityWeek 4.7 million impressions

#CoeliacUKAwarenessWeek 4.3 million impressions

**#CoeliacUKBakes 390,000** impressions





#### Taking on a challenge

For our first ever Challenge Weekend in September, we tasked our community to join together and virtually exercise their way around the UK. **250** participants pledged almost **3,250km** and raised an amazing **£24,000** - more than doubling our target.



Aimee Haydock

250 participants 3,250km pledged £24,000 raised "I thoroughly enjoyed the challenge, the goal, and most of all contributing to a charity that has helped me come to terms with my coeliac disease. Great job!"

Jane Randles

**Roisin Flanagan** 

#### **Championing volunteers**

We're proud of the work our **688 volunteers** and **58 local groups** have achieved in a challenging time. To support them we have connected local group committee members through monthly Volunteer Lounges, offering access to services including out of hours IT support and CybSafe training.

We also celebrated their achievements throughout Volunteers Week, shining a light on volunteers across our organisation, including our wonderful **Member2Member** volunteers who provided "call hugs" to the most isolated in our community during lockdown.



688 volunteers58 local groups



**109** Member Review Panel participants

#### Giving a voice to members

**109 members** participated in the Member Review Panel, helping us to review grant applications from researchers and ensure that our funded research is of benefit to the people we are trying to help. **100%** said they would participate on the panel again.



#### **Supporting GF accredited venues**

Helping our GF accredited venues continue to serve safe gluten free food following the first lockdown was crucial. We helped them carry out a post lockdown checklist to ensure they were following accreditation standards, and our Post lockdown hub helped our community to find out which venues were open and serving a gluten free menu during summer.

8 new GF accredited partners with 46 venues across the UK



In a year of uncertainty, we mobilised our networks to ensure you'd always find up to date, evidence based advice. Whilst the pandemic paused most of our funded research, all projects are now back underway, helping us learn more about the nature and effects of gluten and coeliac disease.

#### Harnessing expertise

We worked closely with our Health Advisory Council and other professional groups who played a vital role in helping to interpret Government guidance on covid-19 for people with coeliac disease, and the Healthcare Professionals (HCPs) supporting them.

10 additional HCPs joined our Health Advisory Council or Health Advisory Network, bringing further expertise from dietetics, gastroenterology and clinical psychology.

#### Who are HAC/HAN?

The Health Advisory Council (HAC) advises the Board of Governors on scientific and health issues, helping to ensure that our information and advice remains expert and up to date. The Council comprises eminent health experts from across the UK.

We also take advice from a broader forum, our Health Advisory Network (HAN). This includes professionals from a range of healthcare backgrounds, who champion our cause in their fields.

#### Representing all nations

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

- 2 virtual meetings of Welsh Parliament Cross Party Group (focusing on the impact of covid-19).
- Correspondence with Scottish and Welsh Health
   Ministers addressing the challenges facing the coeliac
   community and potential of nationwide coeliac disease
   pathways.
- Meeting with Scottish Government and senior officials.
- Letter to Public Health England calling for clarity over guidance on who is considered clinically vulnerable and vaccinations for people with coeliac disease.
- Initial meetings with Northern Irish stakeholders and establishment of Devolved Nations Lead role covering Scotland, Wales and Northern Ireland.
- Health Advisory Council members recruited from across the four nations including new representatives for Wales and Northern Ireland.

#### Leading international change

We participated in the Association of European Coeliac Societies (AOECS) General Meeting. It focused on developing a better future for all, internationally, and we voted on over **50 motions** to influence future policies.

#### Going digital for #RC2020

Following the cancellation of our usual Research Conference, we made our presentations available online, with 7 talks from leading experts. 100 Continuing Professional Development certificates were provided to HCPs as a result of this.

#### **Funding the future**

We awarded **4 sponsored dissertation grants** to students focusing on coeliac disease and the impact of gluten as part of our sponsored dissertation scheme. It aims to place coeliac disease and the gluten free diet on the research agenda of UK academic institutions, whilst commissioning research that underpins our research priorities.

"It took five years to diagnose my daughter with coeliac disease. The problems she faced all this time were painful and depressing.

My research aims to better understand how coeliac disease affects psychological wellbeing and quality of life of young people aged 11-15 and their parents."

**Ummara Akhtar, University of Bedfordshire** 



We couldn't have achieved so much in 2020 without the support of our incredible gluten free community. From the experts in healthcare, research and policy, to our commercial partners, to our thousands of members and supporters – here's some of your highlights:

#### Rallying behind us

In March 2020, we realised our future, like that of many other charities, was looking uncertain. We turned to you to help save our future with an emergency fundraising appeal – and you responded. In just three months, we received over **2,000** donations, totalling an amazing £100,000.

Over 2,000 donations, totaling £100,000 to our emergency fundraising appeal

"Coeliac UK is such an important source of information for people with coeliac disease. Their awareness raising work means we can eat safely. That's why I donated."

**Sonal Shah** 



#### Oh yes they did!

"Our daughter Georgia was diagnosed in 2017. We used so many of your resources to help us and others understand her coeliac disease. Georgia will need support from the charity for the rest of her life so we want to support in any way we can."

Steph and Jaimie Potts of St Philips Dramatic Society, who have fundraised for Coeliac UK at their pantomimes since 2018

#### Raising a glass

In November, you raised over £22,000 at our Wine & Dine Online and auction, whilst having some much needed festive fun.







Telecommunications equipment supplier Corptel donated two prizes to our auction and a further £13,000 throughout the year.

#### **Feeling sporty**

Although many challenge events were cancelled or postponed, lots of you found new ways to fundraise for Coeliac UK and keep active.

"I have found Coeliac UK to be a huge support. It was good to do something positive during lockdown and raise money for a great charity."

Sheila Mathieson, 2.6 Challenge fundraiser





#### Taking the stage

Since Emily Plant was crowned Miss Mansfield (Outstanding Teen) in July 2019, she's raised over £5,000 for her chosen charity, Coeliac UK.

Emily raised over £5,000

#### Leaving a positive legacy

Sadly, many of us lost someone in 2020. Some families have chosen to honour their loved ones by asking friends and family to donate a gift in memory to Coeliac UK, whilst others have decided to leave a gift in their Will. Gifts in Wills raised over £235,000 for Coeliac UK in 2020, and over £1 million since 2016 – a lasting legacy for future generations.



Gwen Tarbuck's family asked for donations to Coeliac UK in honour of Gwen. She had been a long time member who felt that Coeliac UK had been her "life saver".

£235,000 raised by Gifts in Wills - a lasting legacy for future generations



"Three people in my family have been diagnosed with coeliac disease, so we needed all the support we could get. You've been brilliant! The sheer tenacity of the charity in fighting our corner is awesome. I'm always happy to play the Raffles, and to win a prize has put a huge smile on my face."

Katherine Smith won £10,000 in our Christmas Raffle



#### Having a go

Our Raffle players raised an amazing £150,000 in 2020, and Gluten Free Lottery players have raised over £500,000 since 2017.

### **Support us in 2021**

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)