

IMPACT REPORT 2019



















A note from our CEO, Hilary Croft:

"I am delighted to share with you this summary of the impact of our work — a celebration of the final year of our 10 year strategy. I would also like to pay tribute to my predecessor, Sarah Sleet, who led the charity for 13 years. We are indebted to her hard work and wise guidance. Having joined the team mid 2019, I am looking forward to building on the charity's many achievements, and delivering our new strategy that, we hope, will bring even greater impact to the lives of people affected by coeliac disease and gluten related disorders."



Front cover. Clockwise top left to right: Paul Stokes running the Cambridge Half Marathon to raise money for Coeliac UK in March; Laura Embrey puts on a concert in March; Little star Connie Wilson thanks friends for donating £330 at her tea party; Children put on a tea party fundraiser for Awareness Week in London; Young Champion, Caitlin Butterfield, organised a sponsored walk in Pembrokeshire for her friends in May; Kerry Wood and her friends hold a tea party for Awareness Week; Claire Tulloch sharing symptoms to raise awareness.



Raising awareness

Here's how we raised awareness of the symptoms, diagnosis and treatment of coeliac disease in 2019, in our mission to find the half a million people living with coeliac disease symptoms, so they can find the path to diagnosis, treatment and a better future:

Creating new opportunities for diagnosis



NIAMH AND AILISH, aged 11, stars of the Understanding Coeliac Disease comic, produced by the University of Dundee and Coeliac UK for Awareness Week.

52,000 online assessments taken

Awareness Week 2019 took place from 13-19 May. We campaigned to raise awareness of the half a million people in the UK with undiagnosed coeliac disease, whilst specifically highlighting the similarity between coeliac disease and irritable bowel syndrome symptoms.

Our online assessment website, <u>isitcoeliacdisease.org.uk</u> achieved **185k visits**, with **52,000 online assessments completed** (up 4% from 2018). A record **1,000 Awareness Week packs** were sent out, whilst campaign hashtags surpassed **10 million organic impressions** on Twitter and Instagram.

Getting a diagnosis:

Stuart Green and his son, Cameron



66

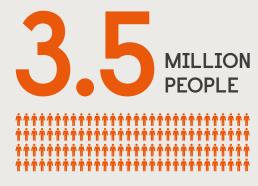
Just before my eldest son, Cameron, turned two, he became very sick. He didn't grow, he was malnourished, he lost interest in everything, and he had absolutely no energy. It was a heart breaking few months for my wife and I, until we finally got the diagnosis that he had coeliac disease.

Thanks to a strict gluten free diet and some great support and advice from Coeliac UK, Cameron bounced back and is now a whirlwind of energy.



Enabling GPs to provide quality support

We distributed **440 information packs** to GPs at the training day events we attended, thanks to our ongoing relationship with Thermo Fisher, helping GPs who are supporting an estimated **3.5 million people**. We also **doubled** the number of contacts signed up to our GP network.



supported through GP activity

Promoting quality gluten free choices

4,000 CROSSED GRAIN

trademark licensed products



Working closely with the food industry, we continued to transform the availability of gluten free food in shops, growing our total Crossed Grain trademark licensed products to almost **4,000**. We also held our second Gluten Free Industry Day in December 2019, with over **100 attendees** from some of the UK's most exciting brands.



Making information easier to find

8 MILLION UNTQUE VISITORS



Visitors spent 7% longer



on our website

We launched our sleeker, more user friendly website in July, making our information easier to find and navigate, especially for mobile users.

1.8 million unique visitors visited our website, and stayed for 7% longer.





We continued to provide independent, trustworthy advice and support to nearly **67,000** members as well as the general public, healthcare professionals and public bodies, so people can live healthier, happier lives gluten free.

30/o growth in membership

Providing the best gluten free food and drink information

With online recipes reaching 1.3 million views, our members were cooking up a storm! Our Food and Drink Information holds over 150,000 products and received over 400,000 views, whilst our Gluten Free Food Checker app was used by 42,000 members and swept the memcom award for Best use of an App.

Our Gluten free on the Move app was relaunched on 1 March 2019 and had **12,400 users** by the year end – an increase of **134**% since relaunch.









Answering more questions than ever





55% membership 24% diet/health/diagnosis 21% food advice

We helped find answers to over **18,000 enquiries** via our Helpline, for which the charity dedicates **£500 per day**.



Thank you for your very kind suggestions and help. I honestly can't tell you enough how much I appreciate your support!

RJ, December 2019

Connecting our members

64% more people using MEMBER2MEMBER

Our community is supported by our network of friendly and experienced **Member2Member** volunteers, available to talk to new members as they embark on their gluten free journey. We matched **64% more people** through this scheme in 2019 than the previous year.



66

The Member2Member volunteer was very supportive and reassuring. They listened. It is lovely to know there is someone there to turn to who understands.



Helping young adults take the next step





220 Moving on packs were distributed to young people heading off to university or leaving home for the first time, with nine universities engaging with Coeliac UK for more information and events.



I really liked the Moving on pack, so thanks for this initiative. I felt looked after, part of a group and not isolated for being coeliac. It was full of practical advice.



Supporting healthcare professionals (HCPs)



DAVID SANDERS and JEREMY WOODWARD, consultant gastroenterologists at the centre of the Rare Disease Collaborative Network for refractory coeliac disease, one of the first to be recognised within the NHS strategy to improve outcomes for patients with rare diseases.

12%

increase in HCP network membership

1365 HCPs signed up to our HCP network (this includes dietitians, nutritionists and those working in a clinical setting), with **160 information** packs sent out to new members.

NICE Consultations

Giving our expert insight at



We participated in consultations with the **National Institute for Health and Care Excellence** (NICE) throughout the year to help drive standards in the diagnosis and care of people who may have other conditions and coeliac disease.

Advising on health policy

Coeliac UK continued working in partnership with NHS **Scotland** on the development of a **new clinical pathway** for patients newly diagnosed with coeliac disease, covering diagnosis, treatment and review. The new pathway is expected to be rolled out further in 2020.

In **Wales**, we worked with the Care in Schools Alliance, exploring **new national guidance** on managing special food requirements in Welsh Schools.



Community

We love our amazing gluten free community! From social media support to local group events and catering training, there are many ways in which we empowered our community to create change together and make life better for everyone living gluten free in 2019.

Growing our online community



OVER 20,000 NEW FOLLOWERS JOINED OUR SOCIAL MEDIA COMMUNITY



123,790 FOLLOWERS BY THE END OF 2019

We surpassed **25 MILLION IMPRESSIONS** across Facebook, Twitter and Instagram in 2019 and reached over **30,000 PEOPLE** on average per day, with a **17% INCREASE** in messages received across social media (that's a total of **39,725 COMMENTS**, **DIRECT MESSAGES AND MENTIONS** from our gluten free community).

Increasing local support



400 volunteers4 local groups200+ local group events

We had over **400 volunteers** working in a range of roles, supporting our community on the ground at local groups with meetings, events and information provision.





I really enjoy organising events and enjoy even more the thanks I get from our members who attend them and get so much out of it. I know we're valued and our members value the support we provide" **Wendy Hughes, Group Organiser for Somerset**.



Giving children a voice



We delivered nearly 200 Young Champions packs to help children educate their peers and feel more confident about their coeliac disease, and saw a 12% increase in junior membership.





Listening to our members

68 MEMBER REVIEW PANEL PARTICIPANTS

68 people participated in our Member Review Panel last year, helping us to review grant applications from researchers and ensure that our funded research is of potential benefit to the people we are trying to help.

Working with experts

We continued to work closely with our Health Advisory Council and Network, which include coeliac disease experts across dietetics, general practice, paediatrics, gastroenterology, psychology and neurology, to ensure that the charity's information and advice remains expert and up to date.

Championing inclusive catering to promote more safe choices



3,400+ UK VENUES GF ACCREDITED

Over **3,400 venues** have now been awarded our GF accreditation, giving people following a strict gluten free diet more confidence and choice when they eat out. Newly accredited venues include a hospital and school caterers, helping people to stay gluten free where it's most important.

"

We are proud of what we have achieved and how our catering staff engaged with the change of arrangements. For any other hospital reviewing their approaches to preparing gluten free meals, we would definitely recommend Coeliac UK and GF accreditation.

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

Bringing our community together



2,400+
PEOPLE ATTENDED OUR
GLUTEN FREE FOOD FESTIVALS

Over 1,200 people and 20 exhibitors attended each of our Gluten Free Food Festivals in York and Cardiff, with a special guest appearance from our Ambassador, Jane Devonshire.





We continued to fund and share crucial research into the nature and effects of gluten and coeliac disease, so that one day, no one's life will be limited by gluten.

Driving knowledge of coeliac disease through research



MORE HEALTHCARE PROFESSIONALS ATTENDED OUR RESEARCH CONFERENCE



2019's Research Conference, titled 'The GF Diet: a solution for everyone' was attended by over 112 HCPs – a 12% increase on 2018. We extended our reach to those who couldn't make it on the day by making the conference presentations available to watch online at www.coeliac.org.uk/RC2019.

Initiating new research



We were thrilled to partner with Innovate UK in March 2018 to fund research worth £750,000 in the food technology, diagnostics and digital care industries, bringing direct benefits to both people with coeliac disease and UK businesses.

<u>3 projects</u> were awarded grants in December 2018 and started in 2019 including:

- development of a less invasive and comprehensive test for the diagnosis of coeliac disease
- better gluten free bread with new improved ingredients
- improving the long term management of coeliac disease.

Following an additional research call in 2019, we have now committed a total of £1 million to research (funds raised between Coeliac UK, Innovate UK and our industry partners). The new project, starting in 2020, will explore the use of artificial intelligence to improve accuracy and speed of diagnosis of coeliac disease.

We also commissioned the University of Nottingham, in a project jointly funded by Crohn's and Colitis UK, to better understand the number of people diagnosed and whether they were previously misdiagnosed with irritable bowel syndrome.



PROFESSOR MARIOS HADJIVASSILIOU, a Consultant Neurologist and director of the Sheffield Ataxia Centre, presented a summary of his latest research, which is partly funded by Coeliac UK, at an event in London in July.

Investigating the importance of prescriptions



Results from our funded research project exploring the impact of the reduction of access to gluten free food on prescription in England, showed that nearly 10% of people reported a severe or very severe impact on their health. We have shared this research with policy makers at NHS England as evidence in support of continued access to prescriptions.



Financial summary

2019

2018

Income £3,840,965 **Expenditure £4,033,050** Income £4,087,319 Expenditure £3,851,528

Proportion of spend:

Raising awareness	27 %
Support and membership	28%
Community	31%
Research	14%

Proportion of spend:

Raising awareness	26%
Support and membership	33%
Community	29%
Research	12 %

Please note that the significant drop in income and increase in expenditure for 2019 can largely be attributed to the receipt of £500,000 from Innovate UK in 2018, which was allocated to fund research in 2019.

You can read a full statement of Coeliac UK's consolidated accounts for 2019 online at www.coeliac.org.uk/plansandreports.





We'd like to say a big thank you to everyone for supporting us in 2019, from our members, fundraisers and followers, to our commercial partners, healthcare professionals and research teams. We couldn't achieve all of this without them, and look forward to their continued support in 2020. Thank you!













