coeliacuk live well gluten free

ANNUAL REVIEW 2017

We heralded in 2017 with a renewed purpose to help our community live a better life, gluten free. We conveyed this through our warmer, more modern look and feel launched early in the year and through our intensified efforts to maintain gluten free food on prescription and encourage catering venues to provide more gluten free options when eating out. With the help of our dedicated community of supporters and volunteers we made good progress in achieving this goal and entered our 50th anniversary year with cause for celebration.



COELIAC DISEASE AWARENESS AT AN ALL TIME HIGH

A commissioned survey* showed public awareness of coeliac disease had increased from 65% in 2015 to 80% in 2017. We believe our work continues to be a driving force behind this change.

*YouGov omnibus survey 2017



BOOSTING DIAGNOSIS AND CARE A successful campaign to save prescriptions in England

In one of the biggest responses they'd ever seen, nearly 8,000 in total, the Department of Health and Social Care ended their national consultation on gluten free food on prescription.

With the government's decision to restrict the categories of foods available on prescription to gluten free breads and flour mixes – a measured response in light of the financial issues impacting the NHS – it was a clear win in terms of the coeliac community's impact on the final decision.

However, the battle has not stopped with more hard work needed to persuade clinical commissioning groups (CCGs) who've already ceased prescribing gluten free food to reverse their policy in light of the decision.

- > Evelyn Well done, CoeliacUK!!! No doubt it was a hard battle, well fought.
- > Dawn Brilliant news :) Thank you for all your hard work for coeliacs!
- > Nina Great news. A big thank you to all at Coeliac UK for your hard work on this.
- > Peter Well done Coeliac UK, thanks for sticking up for coeliacs. This is a sensible and pragmatic decision.

We continued to drive more people to check for coeliac disease

Two years on, the diagnosis campaign continues to raise awareness of coeliac disease and drive more people to the online assessment to check their symptoms. Since the campaign launched:

- 234,000 people have visited the campaign website
- over 100,000 people have taken the test
- 10 million people saw the television advertisement. Thanks again to Thermo Fisher Scientific and Marks & Spencer who supported the campaign.



Meanwhile in Scotland, diagnosis awareness at local community level and via PR and media activity will be boosted by a £9,000 grant from Awards for All Scotland, received in September 2017.

2018 PLANS: we will continue to promote the online assessment tool nationally to improve diagnosis rates while in Scotland we will continue to play an active role in improving the experience of patients with coeliac disease by working on the Scottish Government's new NHS Patient Pathway. In Wales we will continue to push the use of a GP audit tool which will help identify and manage patients with coeliac disease better.



GLUTEN FREE - MORE CHOICE AND LESS RESTRICTION



We launched our Gluten Freevolution campaign with a series of animated videos featuring Cyril the duck, voiced by our patron Caroline Quentin, as he navigates his way through the perils of eating out without gluten. The videos exceeded our target with over 119,000 views. The campaign

also promoted a new gluten free catering manual to the food industry which was endorsed by the Food Standards Agency and was

downloaded over 700 times. We were very grateful to Marks & Spencer for their £30,000 sponsorship of our campaign materials.

Our GF accreditation scheme continued with 3,348 venues now carrying GF accreditation, including Miller and Carter Steakhouses (Mitchells & Butlers). We continued our efforts to increase access to gluten free products through our Gluten free Guarantee (GfG) and food licensing schemes. 77 new licensees adopted our Crossed Grain symbol, while the number of GfG retailers remained static although discussions are ongoing.

2018 PLANS: we will continue to sign up supermarkets to our Gluten free Guarantee programme, and promote gluten free accreditation and our Gluten freevolution message to the catering industry.

FUNDING BOOST FOR RESEARCH

2017 saw the building blocks for our ± 5 million Research Fund put in place, including:

- establishing our 10 most important research priorities through a collaborative priority setting exercise with the James Lind Alliance involving patients and clinicians
- establishing a new Research Strategy Board led by Professor Alan Perkins as the Chair and six others with a wide range of expertise.

All in all we spent just over 5% of our total income in 2017 on research which reached our objective to spend a minimum of 5% of income in any one year.

2018 PLANS: launch our first round of grants as part of the Research Fund through a special partnership with Innovate UK to fund research into better diagnostic testing, technology to support self help and to improve gluten free food production. Innovate UK are contributing £500k to the research call which will be supplemented by £250k from our own funds and the remaining money from companies applying to the Award.



VALUED SUPPORT AND SERVICES

Hand in hand with our new look and feel we wanted to improve our support to members through more relevant services depending on how experienced people were living gluten free. We enhanced our food information service with recipes our Home Economist created for our Home of gluten free recipes, and provided allergen and nutritional information service for over 100,000 products on our online Food and Drink Information service. We used our improved offering to welcome back over 2,000 members who had left the charity altogether.

We provided more tailored support to children and their families with a Young Champions pack which proved extraordinarily popular and improved our service for our Welsh speaking members with more material translated into Welsh and bilingual promotional material. Our first ever Welsh Gluten Free Food Show in Cardiff proved an overwhelming success attracting over 1,400 visitors.

2018 PLANS: we will continue to improve our Home of gluten free recipes to include filmed content helping members master the techniques of cooking without gluten. Our under thirties group GUTs will also be developing resource material to help university students navigate their way through the tricky waters of cooking on their own or in shared accommodation. And we will host another Welsh Gluten Free Food show following the success of the 2017 event.

Shaun, aged 8

"My family ordered the Young Champions pack so I could bring it into school to show the class. We were learning about healthy eating and the pack was great to help me show everyone what I can eat to keep me healthy. We had fun playing the games and everyone enjoyed the stickers at the end. The pack was a great way to show my friends all about coeliac disease. I would like to thank my school and teachers because they always look out for me when planning activities which involve food."



IMPROVING EFFICIENCY AND EFFECTIVENESS

Much of the year was spent on cross organisational planning and reworking of policies and procedures to ensure the charity is in good shape to meet its General Data Protection Regulation obligations in May 2018. We also further modernised our IT infrastructure to protect it from external virus threats and attacks, improved recovery capability in case of system failures, and ensured our website continued to provide a non-stop 24/7 service to our members.

PLANS FOR 2018: we will further improve the website with a new user experience being applied to make finding relevant information easier, and a new look to the members' personalised account area to make the online experience more personally relevant.





VOLUNTEERS -THE BACKBONE OF OUR CHARITY

Our volunteers are fundamental to achieving our aims. Overall, volunteers increased to 1,406 from 1,218 in 2016, and we nearly doubled our campaigning volunteers from 387 to 601, whilst slightly increasing our Member2Member volunteers from 190 to 206. Thanks to funding from the Big Lottery Fund, we supported 22 Young Champions to further the work of the charity during the year. And we continue to receive amazing support from hundreds of volunteers who run our local groups throughout the UK.

Across our volunteering opportunities we have demonstrated our commitment to good governance and support, strengthening our local group policies. In 2017 we applied to Investing in Volunteers which is the UK quality standard for good practice in volunteer management and after extensive assessment we were awarded the Standard at the beginning of 2018.

Working for you

BOARD OF GOVERNORS Claire Andrews John Bremner OBE (elected 24 June 2017) Maureen Burnside (co-opted 25 July 2017) James Chappell – Vice Chair Mike Elliott – Chair Dr Mike Forrest (resigned 24 June 2017) Dr Dai Lloyd Margaret Morgan Stuart Pavelin (resigned 24 June 2017) Professor Alan Perkins (appointed 31 October 2017) Kenneth O'Dea (elected 24 June 2017) Professor David Sanders Robert Trice (elected 24 June 2017)

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FINANCIAL SUMMARY

- The charity's total income in 2017 was £3.9m, exceeding 2016's income of £3.8m.
- Increase was mainly due to legacy income of £477k, a £107k grant from Thermo Fisher Scientific and £30k in sponsorship from Marks & Spencer
- Reserves stood at £1.8m, an increase of £159k from 2016.
- Expenditure was £3.8m. Research expenditure during the year decreased from £332k to £204k or 5% of income. However, this figure will increase significantly with the launch of the Research Fund in 2018.



OUR CHAIR, MIKE ELLIOTT

"We worked hard to live up to our promise to help our community live well, gluten free in 2017 with some great improvements to our gluten free services to members, and educating caterers and front of house staff on the seriousness of catering gluten free with our 'Gluten Freevolution' campaign.

The campaign was received well and along with our ongoing diagnosis campaign, 'Is it coeliac disease?', is yielding fruit with public awareness of coeliac disease jumping 15% in just two years. It's hard not to credit such campaigns with helping to elevate the disease to a level of public awareness not seen before in our 50 year history. And with our successful campaign to save prescriptions, the charity has entered its 50th celebrations with a much needed boost and impetus to continue to strive for a better future for everyone needing to live gluten free.

Achieving a better future means finding better answers to coeliac disease and our 2017 activity put us in a stronger position to launch our £5 million Research Fund in our anniversary year. With better public understanding and more government support for coeliac disease, this ambitious goal could be readily achieved."

