

ANNUAL REVIEW 2018

A note from our Chair

2018 was our 50th Anniversary year, a milestone for the charity and the amazing community we have. Community was certainly the focus for the year, as we celebrated how far we've come and the special contribution of so many who have done so much over the last 50 years. Thank you to everyone who took part and made a special year even more so. This was a time to remember when we had less knowledge of coeliac disease and celebrate how much more we know now, whilst recognising there is more to do to develop our understanding. Hence we looked to the future too, with the launch of our exciting Research Fund, which got off to a flying start after a commitment of £500k from Innovate UK matched by £250k from the charity's reserves, underpinning our first research call for the Fund. We want to see a better future for people with coeliac disease and this Fund will get us closer to the day when no one's life will be limited by gluten.

Mike Elliott, Coeliac UK Chair, Board of Governors



Diagnosis and care

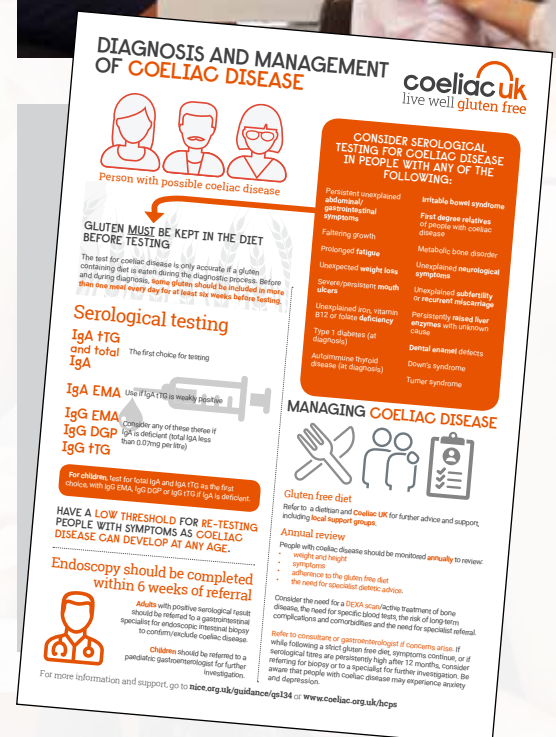
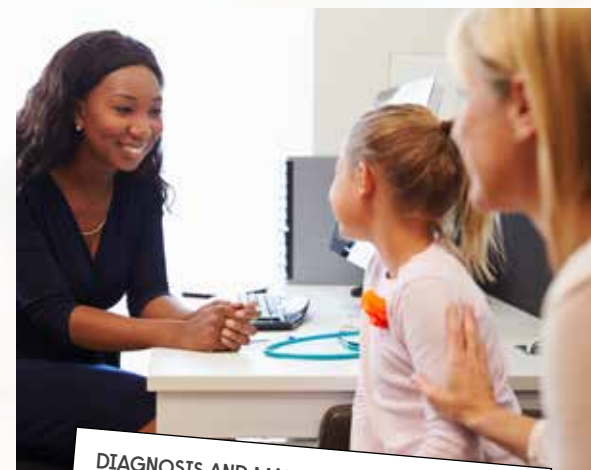
- **We fought for the future of prescriptions** with our campaign which resulted in the announcement from the Department of Health and Social Care to retain access to gluten free food on prescription but restrict the categories of food available. We continue to lobby CCGs that have already ceased prescribing gluten free food to reverse their policy in light of the decision.
- **Our *Is it coeliac disease?* campaign brought a further 50,000 people closer to understanding their symptoms** through our online assessment. We are extremely grateful to ThermoFisher for their ongoing support.
- **We increased our GP connections tenfold** with events throughout the year to engage with the gatekeepers to diagnosis and support improved knowledge of coeliac disease.
- **We continued to work closely with NHS Scotland** on the development of a patient pathway to help patients get an accurate and timely diagnosis.
- **In Wales we took over coordination of the Care in Schools Alliance** representing over 20 health charities and bodies across Wales to engage with the Additional Learning Needs Act 2018 and its associated guidance, to better support children with coeliac disease in school.

"My mum was diagnosed with coeliac disease and, after reading the article in your magazine about symptoms in children, we were convinced my daughter had coeliac disease too. She then got diagnosed and said to me one day, 'mummy it doesn't hurt when I eat anymore!'"

Helen

2019 plans

- Continue our *Is it coeliac disease?* campaign to improve diagnosis with further funding from ThermoFisher Scientific.
- Complete our work on the evidence base for post diagnosis care and understanding what people are eating through our Coeliac Diet and Nutrition Survey (CDNS).
- Develop a self care model for people with coeliac disease and scope out the services needed to support it.
- Develop Wales wide special diet guidance for Local Authority caterers.



NICE guidelines infographic we created for GPs (available to download from www.coeliac.org.uk/diagnosis).

Authoritative support and quality services

- **We grew our community to over 65k members**, welcoming nearly 2k members who came back to the charity. We introduced a new two year membership and December's new joiner rate was the highest it's been in four years.
- **Digital service improved** with half our members now benefitting from our Gluten Free Food Checker app. The Home of Gluten Free Recipes is more popular than ever with nearly half a million page visits.
- **To better support young people, we developed a Moving On pack** with our under thirties group, GUTs. Since its launch in September, **525 packs** were sent out, to high praise. Thanks to the James Tudor Trust for supporting the project.
- **We grew our community in Wales**, welcoming over 1,400 people to our largest ever show, the second Wales Gluten Free Food Show. Media including the BBC, ITV and S4C covered the show.

2019 Plans

- Revamp our website and redesign our venue finder app - Gluten Free on the Move.
- Introduce more filmed content in our Home of Gluten Free Recipes, helping members master the techniques of cooking without gluten.
- Launch our Live Well Gluten Free magazine on food and lifestyle and relaunch Crossed Grain magazine focused on charity activities.



We took nearly 18,000 calls on the Helpline in 2018.

"They are a life saver, any and all questions answered and the app is great! Worth every penny of the subscription." Rachel

Unrestricted eating out



- **So that eating out keeps getting easier**, we pushed our online training and guidance for caterers which had **1.2k downloads** and exceeded our online course target with over **1.3k sessions** taken.
- **We exceeded our single site target with 22 new venue sign ups** to our GF accreditation scheme, taking us to **3,200 accredited venues** across the UK so you can find choice on your high street.
- **We ensured the robustness of our GF accreditation scheme by undertaking 290 audits. 77% of sites achieved an A rating** and a further 16% a B. Only 2% of audits recorded a fail and all passed in the required retake within two weeks.

2019 Plans

- Redevelop our online catering module and review our catering guidance materials, deliver eight newly accredited restaurant chains and 20 individual outlets.
- Use the results of our eating out survey to inform our influencing of policymakers and the catering industry.

"Coeliac UK helped us ensure that we had everything in place to manage cross contamination and our gluten free customers are massively important to our business."

Adele Carnell, Owner of Filmore & Union, GF accredited venue chain

Good quality gluten free products

- **To gain valuable insights we surveyed our members** on shopping habits to inform future work in this area. Nearly **5k members** responded.
- **Over 3,000 products and over 200 companies** are now using the **Crossed Grain licensed trademark on their products** – the extra mark of safety for gluten free products.

2019 Plans

- Use the Shopping Habits survey to engage further with food professionals on new developments in gluten free food.
- Bring industry experts together around key gluten free issues and business opportunities with a Gluten Free Business Boot Camp in June 2019.

Long term solutions through research

- We ensured a clear direction with our new research strategy and Research Strategy Board which was recognised with full membership of the Association of Medical Research Charities.
- With your help we have identified a list of ten top research priorities for coeliac disease. Our priority setting partnership brought patients, their carers and health professionals together, and worked through an initial list of over 2,500 questions to find the right areas for us to fund.
- We delivered 12 Research Talks around the UK, including Belfast, Cardiff and Glasgow, speaking to over 1,000 people about the discoveries our research funding has delivered and the exciting studies currently underway.
- We launched our Research Fund so we can keep investing in a better future for people needing to live gluten free. We were awarded £500k by Innovate UK to address three areas: improved diagnostic techniques, improved gluten free food technology and self care support technologies. We also committed £250k of the charity's own funds and, including the required contribution by companies involved in the applications, around £1m will be available for new research. Huge thanks to Innovate UK.



2019 Plans

We will complete our joint Innovate UK research call and develop further partnerships for joint research calls in the year.

"Taking part on the Member Review Panel was a great opportunity to have your voice heard." Debbie

We are hugely grateful to all of our members and supporters who have contributed to our Research Fund so far – to a value of over £150k. Your support is building a research base which will make a real difference for future generations and help us to lever funds.

Improving our efficiency and effectiveness

- The introduction of General Data Protection Regulation (GDPR) meant a major piece of work to achieve compliance. Automation of the processes will be completed in 2019.
- We were thrilled to achieve Investors in Volunteering at the beginning of the year.
- We increased our donations from individuals and income from raffle and lottery by 26%. And across the year for every £1 we received, 78p was spent on our charitable activities.

2019 Plans

- Develop further volunteer opportunities in our peer support scheme, Member2Member, so more people get help adjusting to life after coeliac disease.
- Focus on university students to promote awareness and support in the higher education sector.

"Remembering what it was like when I was first diagnosed motivated me to try and help others with coeliac disease. You soon discover so many unique stories and experiences that can be shared with others to hopefully improve their lives and understanding on, not just coping, but flourishing going forward." Paul, Group Organiser, Thames South East Local Group



Board of Governors

Claire Andrews
 Ray Bremner
 Maureen Burnside (elected 23 June 2018)
 James Chappell – Vice Chair
 Mike Elliott – Chair
 Dr Dai Lloyd (resigned 7 June 2018)
 Margaret Morgan
 Kenneth O’Dea
 Dr Anita Patel (co-opted 30 October 2018)
 Professor Alan Perkins (elected 23 June 2018)
 Professor David Sanders
 Reshma Shah (co-opted 30 October 2018)
 Robert Trice

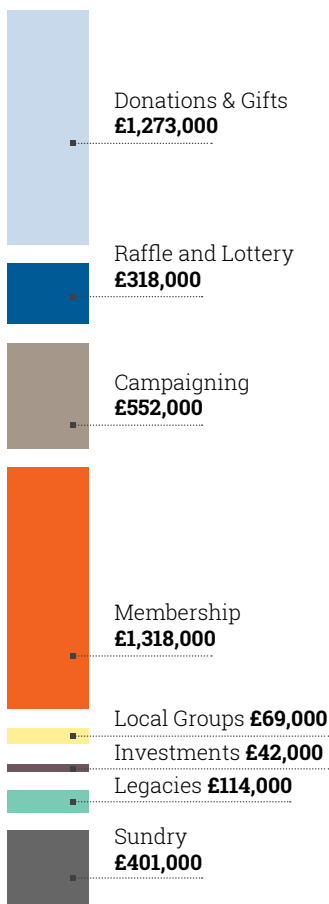
Thanks to all the brave fundraisers who ran, swam, baked, walked, dressed up, dressed down, spoke, sang, jumped, danced, ate, cycled, played and anything else to raise funds for Coeliac UK and celebrated our 50th Anniversary with us. **THANK YOU!**



Financial Summary

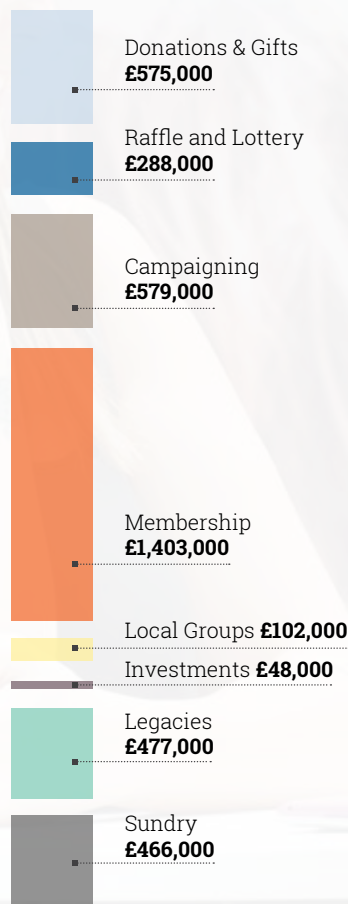
- **The charity’s total income 2018 was £4.1m, an increase of 5% on 2017.** This was mainly due to the grant of £500k awarded by Innovate UK (a Government body tasked with investment in innovation and research) which will be restricted for expenditure under our Research Fund.
- **Reserves stood at £2m, an increase of £200k from 2017.**
- **Expenditure was £3.9m.** Research expenditure during the year increased from £204k to £469k or 11% of income.

Income 2018



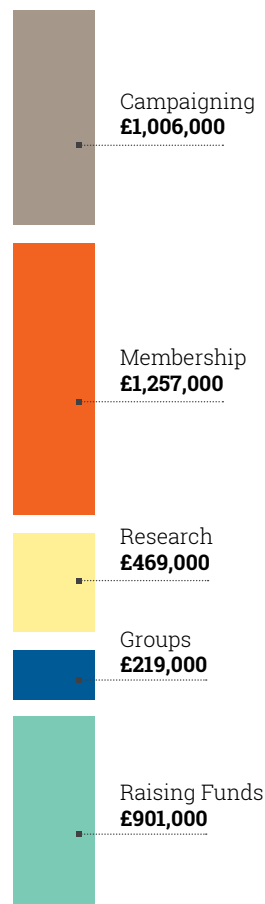
Total Income
£4,087,000

Income 2017



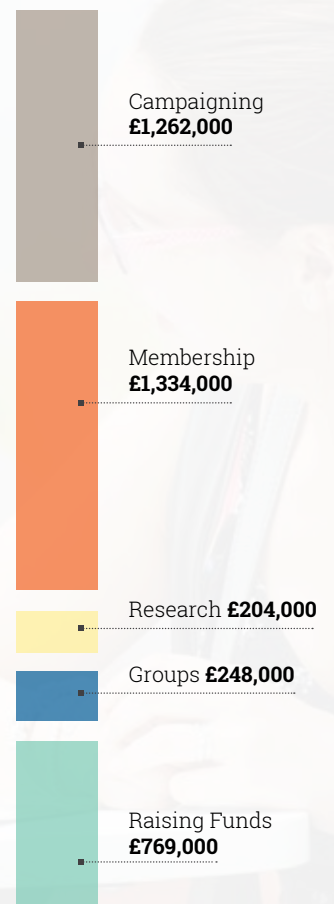
Total Income
£3,938,000

Expenditure 2018



Total Expenditure
£3,852,000

Expenditure 2017



Total Expenditure
£3,817,000