



Research Fund Impact Report

August 2021


coeliacuk
live well **gluten free**

Introduction

In 2018 we launched our Research Fund, to support our Ten Top Research Priorities and change the future for people with coeliac disease and gluten related conditions.

Three years on, how is your support making a difference? Find out in this report.

Leading the way to a breakthrough

Prof Alan Perkins, Chair of the Research Strategy Board and Coeliac UK Trustee

"I was delighted to be part of the launch of Coeliac UK's Research Fund in 2018. Setting up the building blocks for this amazing initiative was no small task, but set us on the path to success. Thanks to a fantastic collaboration with the James Lind Alliance and a superb network of stakeholders, our research priorities were identified and these continue to drive us forward to research excellence.

"This crucial work laid the foundations for Coeliac UK to deliver a meticulous research review process and meet the exacting standards of the Association of Medical Research Charities (AMRC). Our continuing membership of this organisation means that our research capability is better than ever. Thank you to everyone who has supported our Research Fund so far. I hope you will continue to be part of our future – leading the way in driving clear and significant breakthroughs in coeliac disease and other gluten related immune conditions."



Thank you to everyone who has supported the Research Fund

Inspiring change

Hilary Croft, Chief Executive Officer, Coeliac UK



"The quality and range of projects supported by Coeliac UK's Research Fund are world class. They cover the myriad of ways that coeliac disease impacts on people's lives. At Coeliac UK we know and understand the issues: the challenges of diagnosis, the lifelong anxiety around the gluten free diet, the isolation the disease can cause, and the wider impacts on health and wellbeing.

"We have spent the last 50 years and more fighting to improve life for people with coeliac disease. But not everyone has taken the condition as seriously. As a result there has been a lack of major investment in research into both coeliac disease and gluten related immune conditions. Research funding is significantly lower than for some other autoimmune or gut related conditions despite the fact that coeliac disease affects nearly 700,000 people in the UK.

"This is why your donations and support are so important. Without your help, we simply could not fund these projects - thank you. I'm proud that Coeliac UK is the leading charity funder of research into coeliac disease and the gluten free diet, investing well over £3 million in the last 15 years. I hope this report shows you the tangible benefit that your donations to our Research Fund have supported, and the impact that your continued support can have in future."

Ten Top Research Priorities

Our Ten Top Research Priorities identify the key areas of focus for our Research Fund, as decided by our Priority Setting Partnership, in collaboration with the James Lind Alliance and with feedback from people with coeliac disease, their carers and healthcare professionals.

Read more about these at www.coeliac.org.uk/researchpriorities

The priorities fall under these key areas for improvement:

Better scientific understanding

- Understanding links to other conditions
- Finding the triggers
- Understanding the causes of refractory coeliac disease
- Understanding neurological forms



Prevention

- Preventing the onset



Diagnosis

- Working towards less invasive tests



Management

- Increased food safety
- Improved post diagnosis support



Health services

- Better support for healthcare professionals



Cure

- Finding a cure



Funds raised for research: 2017 – present

Allocated funds from Coeliac UK reserves	£236,038
Innovate UK grant	£500,000
Funds donated by our community	£328,284
Total funds:	£1,064,322

- We have already jointly funded four great projects with Innovate UK, totalling £750,000. Read on for updates on all four.
- And we've got exciting projects in the pipeline:
 - Research to support the diagnosis of neurological forms of coeliac disease, read on for more information
 - Research focusing on coeliac disease in children and young people, more information coming soon

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UKRI Innovate UK

Working towards a better future

Since the **Research Fund** was launched, Coeliac UK, Innovate UK and our industry partners have jointly funded four major projects. Find out more about these projects below:



Development of a less invasive and comprehensive test for diagnosis of coeliac disease

Grant awarded: £198k

Obtaining a diagnosis of coeliac disease can be challenging, and there are limitations to the current diagnostic methods.

Nonacus Ltd and researchers at the University of Cambridge are working together to develop, test and manufacture a new and improved diagnosis method for coeliac disease.

In people with coeliac disease, gluten is recognised by immune cells called T cells, which trigger an immune response leading to inflammation and damage to the gut. Although most of the inflammation disappears on a gluten free diet, we know there are permanent changes to the gluten specific T cells.

Researchers have developed a machine learning algorithm that can identify people with coeliac disease by looking at the DNA of the gluten specific T cells taken from biopsy and blood samples.

They have tested the new method on a small number of biopsy samples and successfully identified people with and without coeliac disease, **even if gluten has already been removed from the diet**. The team hopes to expand this test to a larger number of biopsies to confirm the results.

You can read more about this development at www.coeliac.org.uk/news/funded-research



Chris Sale, Chief Executive Officer, Nonacus Ltd

The project is also testing the new method on blood samples and if successful, this will allow for a truly revolutionary non invasive diagnosis method.

Head over to our blog to watch a fantastic interview with the team at Nonacus Ltd:
www.coeliac.org.uk/nonacus-blog



An artificial intelligence solution for diagnosis and assessment of small intestinal biopsies in suspected or known coeliac disease

Grant awarded: £175k

Lyzeum Ltd is working with a multi disciplinary team of mathematicians and pathologists from the University of Cambridge and the University of Edinburgh to develop an artificial intelligence solution to improve the accuracy and speed of coeliac disease diagnosis.

In the majority of cases, an endoscopy with a biopsy of the small intestine is needed to diagnose coeliac disease. Biopsies are examined by a trained pathologist, a process that can be time consuming and subjective.

The research team will develop an algorithm that can classify small intestinal biopsy samples as either coeliac disease or non coeliac disease and highlight uncertain cases where an expert opinion is still required.

“ We have four working methods for classifying coeliac disease versus non coeliac disease. By combining these methods, we have achieved over 99% accuracy, with 100% sensitivity (meaning all samples from people with coeliac disease were correctly identified).

“A limitation is that all samples were from one hospital, so we have started sourcing biopsy images from other hospitals, where different methods to prepare the biopsies and different scanners to produce the images will have been used.

“Next we will develop techniques to identify which parts of the biopsy are most informative. This will enable us to better understand the basis for making decisions, which is important for clinical validation and adoption. ”

Dr Elizabeth Soilleux, founder and Chief Executive Officer at Lyzeum Ltd



Watch now

Watch Dr Elizabeth Soilleux explain why this research is so important, both to our community and to her as a mother, in our video interview.

Visit www.youtube.com and search: "Why coeliac disease research?"



Better gluten free bread with new improved ingredients

Grant awarded: £181k



Industry partners Nandi proteins Ltd, Agrii, AB Mauri, and Finsbury Food Group are working together with researchers at Heriot Watt University to develop gluten free bread with new improved ingredients.

At the moment, gluten free ingredients such as egg white can be used as a gluten replacer in gluten free bread. This project aims to find alternative gluten replacers and to produce a final product that tastes and feels more like a gluten containing loaf of bread.

The project will identify methods for extracting proteins from three types of underused UK grown crops and test their functionality in bread recipes.

Check out our webpage on the project to find out more: www.coeliac.org.uk/betterGFbread

“ The project has now demonstrated the successful replacement of egg white in a gluten free bread formulation using functionalised faba bean protein, and the team is now looking forward to factory scale trials of the ingredient. Faba bean, as a sustainable crop widely grown in the UK, appears to be an interesting plant based provider of gluten functionality and an alternative to egg white in bakery products. The partners are exploring additional bakery applications. ”

Peter Smith, Principal Investigator, Agrii



Using software to improve the long term management of coeliac disease

Grant awarded: £195k

Cievert Ltd are working with the Royal Hallamshire Hospital, Sheffield to develop and test Cievert's software, Penguin, to support people with coeliac disease.

Penguin will deliver a personalised online questionnaire to assess how people are coping with coeliac disease and managing the gluten free diet. The software will be able to examine the patients' answers and identify those who need additional support. Patients will be able to access Penguin using any standard web browser.

During the development process, Penguin was trialled by Coeliac UK volunteers. A big thank you to the 200 volunteers who tested Penguin and provided feedback. Penguin is now being tested locally at Sheffield Teaching Hospital NHS Trust and other NHS Trusts across the UK.

Over the last year, there has been an increased interest from patients and clinicians to explore digital health solutions like Penguin. This has meant that the project has been able to recruit more patients from more hospitals across the UK. The project has also been extended to include children with coeliac disease as well as adults.

Check out Cievert's guest blog to find out more.
Visit www.coeliac.org.uk/cievert-blog



*Chris Kennelly,
Managing Director,
Cievert Ltd*

Thank you



Thank you so much to everyone who has supported our Research Fund. Without your help, we simply wouldn't be able to make the progress you've read about in this report. Your donations make life changing research possible, bringing us closer to a better future for people with coeliac disease.

But our work is far from over, and more funding is needed to ensure research can continue. Help us keep going by making a donation at www.coeliac.org.uk/rf-donate

Coming up

Supporting students to research coeliac disease and the impact of gluten

Since 2016, we've been providing grants of up to £1,000 to encourage undergraduates or postgraduates studying at UK institutions to focus their projects on coeliac disease and the impact of gluten.

The main objective is to put coeliac disease and the gluten free diet on the research agenda of UK academic institutions, whilst commissioning research that underpins our research priorities.

We are pleased to announce that thanks to the generosity of the Violet M Richards Charity we will be funding our 2021 call for sponsored dissertations, this autumn. Look out for more information in the coming months. You can check out our 2020 sponsored dissertations at www.coeliac.org.uk/sd2020

Bringing great minds together

Our Science Workshop will bring together expert researchers from across the world to identify projects which will help us tackle our Ten Top Research Priorities. Look out for more on this in the next few months.



Funding research to support the diagnosis of neurological forms of coeliac disease

Understanding more about the neurological forms of coeliac disease is a research priority for Coeliac UK. Gluten ataxia has severe consequences, causing neurological damage to the brain (particularly the balance centre) with detrimental effects on quality of life.

Diagnosing gluten ataxia has until recently been a difficult process and it is believed that many cases are still being missed due to lack of a clearly defined diagnostic pathway.

We are close to funding a research project to cover the adoption and monitoring of a new diagnostic process in specialist neurological clinics in the UK, to help establish new guidelines and to improve the lives of people with gluten ataxia.

Help us to get this project up and running by donating to our Research Fund at www.coeliac.org.uk/rf-donate

Make a donation

Help us continue supporting vital research into coeliac disease, by making a donation today.

Visit www.coeliac.org.uk/rf-donate or send your donation by mail to:

Research Fund

Coeliac UK Office, 3rd Floor Apollo Centre, Desborough Road, High Wycombe, Buckinghamshire, HP11 2QW

Keep up to date

For the latest news and updates on our research activities, visit www.coeliac.org.uk/currentresearch or follow us on Facebook, Twitter and Instagram.

 facebook.com/CoeliacUK  [@Coeliac_UK](https://twitter.com/Coeliac_UK)  [@CoeliacUK](https://instagram.com/CoeliacUK)

Or sign up to our monthly Enewsletter at www.coeliac.org.uk/newsletter-signup



www.coeliac.org.uk

