

COELIAC UK'S TOP 10 RESEARCH PRIORITIES

The key areas of focus for our Research Fund, as decided by our Priority Setting Partnership with feedback from people with coeliac disease, their carers and healthcare professionals




coeliacuk
live well **gluten free**



HOW DID WE CHOOSE OUR RESEARCH PRIORITIES?

Our Priority Setting Partnership (PSP) on coeliac disease has been working on establishing research priorities for coeliac disease since May 2017

In 2017 Coeliac UK teamed up with the James Lind Alliance, experts in priority setting partnerships (PSP), bringing people with coeliac disease, their carers and healthcare professionals together to agree a top ten list of research priorities.

Since May 2017, the PSP has undertaken a number of stages, including:

- a survey for participants to submit their questions about coeliac disease which may be answered by further research (this includes the other immune conditions caused by gluten eg dermatitis herpetiformis and gluten ataxia)
- categorisation of the submitted questions by an information specialist and Steering Group

- a check of the evidence base to ensure the research hasn't already been completed
- a second survey to rank the research questions and provide a targeted list to take to a workshop.
- a one day workshop involving patients, their carers and healthcare professionals to discuss and agree a top ten list of priorities.

A huge thank you goes out to everyone who participated in our surveys, attended the final workshop, and dedicated their time to the Steering Group. Find out more about the PSP at www.coeliac.org.uk/researchpriorities.

Thanks also to the key partners involved in the PSP for coeliac disease:



James
Lind
Alliance

Priority Setting Partnerships



Ataxia UK



I. FINDING THE TRIGGERS FOR COELIAC DISEASE

We need to find the risk factors or triggers to the development of coeliac disease. Do they determine when someone will develop coeliac disease and/or predict how severe disease associated symptoms or complications will be?

PHOEBE AND RUBY



Twins, Phoebe and Ruby were diagnosed at separate times and the initial symptoms for each of them were very different. Phoebe had reflux and severe constipation whilst Ruby who was diagnosed later had skin rash and tummy issues. They have also been diagnosed with an autoimmune thyroid condition.

Coeliac disease affects us both and that can make each other sad. We want to stay well but it's hard and it's good that there are people that are trying to help.

2. BETTER SUPPORT FOR HEALTHCARE PROFESSIONALS

How can healthcare professionals be best supported to accurately diagnose and manage coeliac disease and other gluten related autoimmune conditions to achieve earlier diagnosis and improve patient care?

MAUREEN, 79



It took 40 years for Maureen to be diagnosed with coeliac disease. As a result, she is now wheelchair bound due to osteoporosis and neurological issues affecting her balance.

“The coeliac disease has put me in the wheelchair because most people don’t realise it affects the balance in the brain eventually if you’ve been as long as me with it, so I can fall and because I’ve got osteoporosis then the falling is serious. The main reason I’m telling my story is so you can stop a younger person from becoming like me.”

3. UNDERSTANDING NEUROLOGICAL FORMS OF COELIAC DISEASE

What is the spectrum of neurological forms of coeliac disease and how does the neurological dysfunction develop? How are they best diagnosed and managed?

KERRY, 39



Kerry's life has never been the same since the debilitating symptoms of gluten ataxia, as a result of suffering from coeliac disease, took hold and changed the course of her future. Ataxia causes speech difficulties and loss of control over the right side of her body. The former fitness fanatic had to give up her career plans to be a massage therapist and for others like her, the gluten free diet is not enough to help her manage her condition.

I feel like I can't function normally any more. I'm not the person I used to be, even on a gluten free diet.

4. FINDING LESS INVASIVE TESTS TO RECOGNISE COELIAC DISEASE

Are there less invasive tests for recognising coeliac disease and is it possible to accurately test for the disease once gluten has been excluded from the diet?

LIZ AND HER FAMILY



Liz and her two young children suffered with debilitating gut symptoms for some time before gluten was found to be the cause. Once gluten free, the improvement in their wellbeing was astonishing but Liz was horrified to think how long it took to discover the cause and then reluctant to reintroduce gluten to have them properly diagnosed with coeliac disease. As a researcher in immunology, this spurred Liz on to explore a potential blood test that might detect coeliac disease when people have already stopped eating gluten.

5. UNDERSTANDING THE LINK BETWEEN COELIAC DISEASE AND OTHER CONDITIONS

How can we better understand the associations between coeliac disease and other conditions, for example, Type 1 diabetes and autoimmune thyroid disease, and what factors influence the risk of developing such conditions?

HINESH, 25



Hinesh was diagnosed with Type 1 diabetes when he was 11 years old, and then with coeliac disease only two years ago. His diagnosis for coeliac disease came about after blood screening to understand his fatigue. He has difficulty finding the right gluten free carbohydrates to manage his diabetes.

I was slipping into a diabetic coma and was admitted to hospital. Through various tests and multiple biopsies, they diagnosed me with coeliac disease.

6. FINDING THE BEST POST DIAGNOSIS SUPPORT

What is the best means of follow up management of people with coeliac disease and/or other gluten related autoimmune conditions, including help with sticking to the gluten free diet and prevention of long term health complications?

REBECCA, 41



Diagnosed with osteopenia from undiagnosed coeliac disease at the age of 30 after suffering a hip fracture, Rebecca has been on a 10 year journey back to health. With the help of physiotherapy, a new exercise regime and careful management of her gluten free diet, she is now managing her coeliac disease well.

“It would make a difference getting more information to doctors, into schools so that it’s taken a bit more seriously and the longer term effects understood.”

7. IMPROVING SAFETY FOR PEOPLE EATING OUTSIDE THE HOME

What are the best ways to educate people working in the catering/hospitality industry about the gluten free diet to improve safety for people with coeliac disease when eating out?

NIC, 46



Nic's two young daughters have coeliac disease and this inspired her to become a Food Campaigner for Coeliac UK as she struggles to ensure her daughters can maintain a healthy, safe gluten free diet especially as they enter the school years.

The main improvements I'd like to see in the future are more cafes and restaurants selling healthy, savoury food that is gluten free and free from cross contamination.

8. FINDING A CURE FOR COELIAC DISEASE

How can coeliac disease be cured so that consideration for a gluten free diet is no longer necessary?

CHARLOTTE, 29



Charlotte struggled for years with misdiagnosed irritable bowel syndrome before finally being diagnosed with coeliac disease, but only after losing so much weight she went down four dress sizes. While she's now put on weight, her dermatitis herpetiformis has not cleared yet. But it's the struggle of managing a gluten free diet, especially on a limited budget, which makes it all the more challenging for this young mum of two, and makes her wish for a better future.

"I don't want other people to be in the situation I was in, and if more research can make things easier and make it easier to diagnose... maybe even one day find a cure, that would be amazing."

9. PREVENTING THE ONSET OF COELIAC DISEASE

How can coeliac disease and associated complications be prevented in genetically vulnerable individuals, eg using drugs, vaccinations or modification of diet?

DEBBIE AND HER FAMILY



With three generations of her family all diagnosed with coeliac disease, former scientist Debbie Lane was very keen to become a member of Coeliac UK's Member Review Panel and have a say in how research is directed.

While I don't have the condition, my father was diagnosed at age 30 after suffering symptoms from infancy, and then after my son was diagnosed at age two, my husband subsequently was tested and found to be positive.

10. UNDERSTANDING THE CAUSES OF REFRACTORY COELIAC DISEASE

How can we better understand the causes of refractory coeliac disease types I and II and use this understanding to develop and improve diagnosis and treatment?

JOHN, 52



John suffered from undiagnosed coeliac disease for 50 years before being diagnosed with refractory coeliac disease type II. He continues to suffer from pain as critically, type II does not respond to the gluten free diet and devastatingly, the long term prognosis for those diagnosed with the condition is not good, with less than 50% surviving beyond five years.

“It’s a killer – type II. If we don’t treat it in the right way people will die from it.”

LET'S FIND THE ANSWERS SOONER.

DO SOMETHING.

Donate to the research fund now at
www.coeliac.org.uk/researchfund

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