

News Release

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**First Rare Disease Collaborative Network
on refractory coeliac disease commissioned**

Refractory coeliac disease, a deadly form of the autoimmune condition coeliac disease, receives its first dedicated support from NHS England with the setting up of a Rare Disease Collaborative Network (RDCN) to accelerate research and treatment into this life threatening condition.

Coeliac disease is relatively common with 1 in 100 people in the UK experiencing the condition and can be successfully treated with a gluten free diet for life. Refractory coeliac disease affects 2 to 5% of these patients. They do not get better on a gluten free diet and are more likely to develop a specific type of cancer with fatal consequences.

Prof David Sanders from Sheffield will lead the Network, working alongside Dr Jeremy Woodward at the collaborating centre in Cambridge. The RDCN will be looking to drive improvements in patient outcomes through greater understanding of refractory coeliac disease.

Prof David Sanders said “The outlook for patients with refractory coeliac disease has been very poor with a 50% life expectancy post 5 years. The support from NHS England is wonderful as it will allow us an opportunity to collectively work on improving this awful situation for our patients.”

RDCNs have been set up by the Government recently as part of its Strategy for Rare Diseases with a vision to lead to improved outcomes for patients with very rare diseases which have a prevalence of < 1 in 10,000 of the population.

Earlier this year Coeliac UK, the largest independent charity for people who need to live gluten free, launched a research fund and accompanying fundraising appeal, aiming to raise £5 million to change the future for people with coeliac disease and gluten related autoimmune conditions.

Sarah Sleet, chief executive of Coeliac UK said: “This is the first time refractory coeliac disease will receive the focus from NHS England on new treatments and care that is so desperately needed. Now that we have this crucial recognition, we are working through our Research Fund to ensure we can make the investment and capitalise on this development and help improve the future for patients

suffering with debilitating symptoms and we are delighted that Prof Sanders and Dr Woodward will be leading this collaborative network.”

Coeliac UK is the national charity for people who need to live without gluten, whether due to coeliac disease or another medical condition requiring a gluten free diet.

More information: www.coeliac.org.uk/researchfund.

Ends

Notes to editor

- Coeliac disease is a serious autoimmune condition where the body's immune system reacts to gluten found in food, making the body attack itself.
- 1 in 100 people in the UK has coeliac disease but half a million people in the UK are undiagnosed.
- Average time to diagnosis is 13 years.
- 1 in 4 people diagnosed with coeliac disease had previously been diagnosed with IBS.
- Gluten is a protein found in wheat (including spelt), rye and barley. Some people are also sensitive to oats.
- Coeliac UK has a Helpline on 0333 332 2033 and further information can be found at www.coeliac.org.uk