



April 2018 Newsletter

Welcome to the April issue of the Croydon Group of Coeliac UK's newsletter.

Meeting reminder: AGM followed by Patient Charter – how it could be implemented in Croydon and what it means about the future of your care with Healthcare Professionals in Croydon.

Dr Sanjay Gupta Consultant Gastroenterologist (Croydon University Hospital) and Sarah Sleet Chief Executive from Coeliac UK will be present to help answer your questions about how you can use the Charter to influence the care you receive.

Wednesday 25th April 2018
Time: 7.30 – 9.30 pm
Venue: Purley United Reformed Church
906 Brighton Road, Purley CR8 2LN

If you wish to attend, **please reply to:** Coeliacsurrey@btinternet.com
So that we can cater for the correct number of members.

Easter List on Coeliac UK website



Easter is coming, check the Easter List on the Coeliac UK website to find all the available gluten free Easter goodies!

<https://www.coeliac.org.uk/about-us/news/our-easter-list-is-now-available/>

Awareness Week – 14th – 20th May 2018

Are you passionate about helping other people/ raising awareness of Coeliac Disease? I am looking for some members to volunteer to raise Awareness on Wednesday 16th May. If you would like to help please let me know. For more details email Coeliacsurrey@btinternet.com

COELIAC UK LAUNCH RESEARCH FUND TO CHANGE THE FUTURE FOR PEOPLE WITH COELIAC DISEASE AND GLUTEN RELATED AUTOIMMUNE CONDITIONS

Coeliac UK, the largest independent charity for people who need to live gluten free, this week launches 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.

The research appeal is being headed up by Coeliac UK's patron, actor Caroline Quentin who was diagnosed with the autoimmune disease three years ago. It will boost research efforts into key areas identified and agreed by patients, carers and healthcare professionals. The full list can be found here www.coeliac.org.uk/researchfund.

With the charity celebrating its 50th anniversary this year, there is a greater urgency to find better answers to the disease, which has links to other autoimmune conditions such as Type 1 diabetes and autoimmune thyroid disease and still relies on the gluten free diet as its only treatment.

Sarah Sleet, chief executive of Coeliac UK said: "It is possible through further research, that finding the answers to coeliac disease could enable answers to other devastating autoimmune conditions such as Type 1 diabetes. With more people being diagnosed with coeliac disease each year and with new health complications emerging, it is critical that we make the commitment now to change the status quo and make coeliac disease research everyone's priority."

A video was produced as part of the appeal launch to show the impact of the disease on those affected and can be viewed here www.coeliac.org.uk/researchfund. The video shows the various presentations of coeliac disease including refractory coeliac disease type 2 (which is not responsive to the gluten free diet), osteoporosis and gluten ataxia.

The Fund has already received an injection of £500k from Innovate UK, the UK's innovation agency, which in addition to £250k from the charity, will support a new research competition. Match funding will draw in a further £250k from industry making the first £1 million available from the Fund.

Dr Ian Campbell, Director of Ageing Society, Health and Nutrition, Innovate UK said: "It's fantastic to be working with charities such as Coeliac UK to promote innovations that will have a real, positive impact on people's lives."

Coeliac UK has already committed over £2 million to research projects since 2005 including ground breaking discoveries such as identifying genes associated with coeliac disease and other autoimmune conditions related to gluten. And also funded research towards a vaccine to restore immune tolerance to gluten.

“50 years ago, little was known about coeliac disease and the gluten free diet, bread used to come in a tin and people wrongly thought children would grow out of the autoimmune disease. Fast forward to today and both the disease and the diet are firmly on the worldwide map and 150,000 diagnosed people in the UK now live a better way of life thanks to improved recognition and diagnosis. However, half a million people remain undiagnosed and we need more support to help them get diagnosed and managing their condition with a gluten free diet. But, we also know that there needs to be a more permanent solution to this complex disease, so we are boosting our research efforts and awareness raising as part of our 50th anniversary activities,” Ms Sleet said.

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. Coeliac disease is a serious autoimmune condition caused by a reaction to gluten, a protein found in wheat, barley and rye. People diagnosed with coeliac disease must maintain a strict gluten free diet for the rest of their life if they are to avoid very serious complications such as osteoporosis, infertility and although rare, small bowel cancer.

Donate today at: www.coeliac.org.uk/researchfund.

Research Conference London March 2018..... Jacqui

I was very lucky to be invited to the Patient Forum of the Conference, it was a very informative day, I also met many of those who appear in the Advert, and I realised that after nearly 30 years of being a Coeliac Patient that Coeliac Disease is a very complex disease. The Health Professionals approach used to be a “3D” consultation with the Patient “Diagnose, Diet & Discharge”. Due to the complex nature of Coeliac Disease I don’t believe this can be the case anymore. Another reason to get the Patient Charter up and working for you in Croydon.

.....

Croydon Coeliac Group AGM 23rd April

I / we will be attending: Name:

Awareness Week – Volunteering:

I would like to help Raise Awareness Yes NO

If you answered Yes..

Please indicate what time you would be able to help: 9.00 – 11 am

11.00 – 1.00 1.00 - 3.00 3.00 – 5.00

Please reply by email to Coeliacsurrey@btinternet.com

Every effort has been made to ensure the accuracy of information contained in this newsletter. Furthermore, any articles, contributions or opinions contained herein are printed in good faith. However Coeliac UK and the Croydon Group can accept no responsibility for any errors or items this newsletter contains.

Coeliac UK – A registered Charity and Company Limited by Guarantee and Registered in England.
Registered Charity Number: 1048167 Company Number: 3068044