



The First World IBD Day hits the UK

National and International awareness of IBD (Inflammatory Bowel Disease - Colitis and Crohn's Disease) grows across the UK

10th May 2010, St Alban's, Herts, UK. The National Association for Colitis and Crohn's (NACC) is rolling out Colitis & Crohn's (IBD)Month during May, including the BBC Radio 4 Appeal, major fundraising Walks and involvement in the first World IBD Day. The array of events includes two large city Walks, the first in London and the second in York on the 23rd May, plus a multitude of NACC Group awareness events and fundraising activities all around the country.

Marking NACC's 30 years as the leading source of information and support for people with Inflammatory Bowel Disease (IBD), celebrity Ambassador, Carrie Grant will be presenting the BBC Radio 4 appeal on the 23rd and 27th May. Carrie has had Crohn's Disease for the past 25 years and has been a member and staunch supporter of NACC, which has been of "tremendous help" to her. The Radio 4 Appeal will highlight the work of NACC and will call for donations in order to provide grants between £25 and £300 to IBD patients – covering various needs, from supplying new bed sheets to providing a washing machine.

The London Walk on the 8th May, opened by Carrie Grant, saw a record 670 participants walk round some of London's key landmarks, despite inclement weather, to raise valuable funds for the charity. Later in the month, celebrity Ambassador *Emmerdale* actor Jeff Hordley will be cheering on the York Walk, now in its 5th year, a testament to the tireless efforts of NACC members, volunteers and their friends and family.

For the first time, NACC will be taking part in the inaugural World IBD Day, led by patient organisations representing 27 countries on four continents. World IBD Day will be celebrated on 19th May, 2010, as part of NACC's Colitis & Crohn's Month activities. This reflects the growing acknowledgment of these previously under-recognised diseases which are typified by symptoms of relentless diarrhoea, bleeding, pain, profound fatigue, eye, skin and joint problems, and impaired growth in childhood.

NACC CEO Richard Driscoll added, "NACC is playing a leading role in raising awareness of IBD as part of the first World IBD Day activities. We have planned an awareness-raising reception at the Scottish Parliament which will be attended by the Minister for Public Health and Sport Shona Robison on the eve of World IBD Day. The key messages will be the need for more research and for better organisation of IBD healthcare in line with the national standards published in 2009. Over the past 43 years, NACC and the other international patient organisations that are leading the World IBD Day events have collectively contributed \$250 million to IBD research."

The overall theme for the 2010 Colitis & Crohn's Month has focused on the need for a national IBD Patient Register, and the 'Step Up and Be Counted' activities continue this month. NACC is asking the public to log on to www.stepupandbecounted.org.uk to petition the Department of Health for a Register of IBD patients to improve patient care and the quality of long-term medical research.

The precise numbers of patients with IBD are, at best, only estimates and the current estimation is approximately 240,000 people affected in the UK. At present only 39% of UK hospitals hold a database of their Colitis and Crohn's disease patients. The aim of the IBD Patient Register will be to ensure quality care for all patients, gather data for research into a cure and identify patients who are not in a follow-up system and may be at risk of complications. NACC is aiming to present thousands of votes to the Department of Health this year. **ENDS**

For further information on this release, please contact Sarah Rogers or Emily Dean at The NACC Press Office on Tel: 01252 790 507 or email emily@healthcare-pr.co.uk

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NACC – Meeting the challenge of Colitis and Crohn's disease

Editor's Notes

What is IBD?

Ulcerative Colitis and Crohn's Disease are lifelong conditions, most commonly presenting in young adults, adolescents and children and affecting men and women about equally. The diseases cause inflammation and ulceration in the colon and rectum (Ulcerative Colitis) or anywhere in the gastrointestinal tract (Crohn's Disease).

The main symptoms are very urgent and frequent diarrhoea, pain, profound fatigue and anaemia, with, for some patients, associated inflammation of the joints, skin, or eyes. Malnutrition and weight loss are common. The diseases follow an unpredictable relapsing and remitting course with significant variation in the pattern and complexity of symptoms that may affect each patient.

Key facts

- About 240,000 people in the UK have IBD, approximately 400 patients per 100,000 population.
- The cost of IBD to the NHS has been estimated at about £720 million per annum, based on the prevalence and an average cost of £3,000 per year per patient.
- There is no cure. Cause is likely to be multifactorial, a combination of genetic predisposition and environmental triggers.
- These are lifelong conditions and most commonly first present in the teens and twenties (25% present in adolescence; median age at diagnosis is 29.5 years).
- Men and women are diagnosed in equal numbers.
- Between 50% and 70% of patients with Crohn's Disease will undergo surgery within 5 years of diagnosis. In Ulcerative Colitis lifetime surgery rates are about 20-30%.
- Patients with extensive disease may develop complications which are potentially life-threatening.
- There is an established link between IBD and an increased risk of developing colorectal cancer.
- The lifetime medical costs associated with the care of IBD can be comparable to major chronic diseases such as diabetes mellitus or cancer.

The BBC Radio 4 Charity Appeal will take place on the 23rd May at 07:55am and 21:25pm and again on 27th May at 15:25pm. More information and personal stories will be available nearer the time at www.bbc.co.uk/radio4/appeal.

World IBD Day is on the 19th May 2010. Patient groups from the United States, Canada, Australia, 23 European nations, and Brazil are working to draw awareness to IBD. More information can be found at www.ibdday.bvsalud.org/.