

New European Survey of People with Colitis and Crohn's Disease highlights that "Brits Needs To Communicate Better"

21st March 2006, British Society for Gastroenterology Congress, Birmingham, UK. A new pan-European survey of 5,636 people from seven countries conducted by the European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA) highlights the serious challenges faced by people living with these two chronic inflammatory bowel diseases which are estimated to affect up to 240,000 people in the UK and which can prevent those affected from leading a normal life.

The Survey indicates that compared with our European cousins, British 'reserve' continues to rule when it comes to discussing symptoms and treatment with our doctors. It appears that British patients are relatively unwilling to discuss the distressing and often embarrassing symptoms of Colitis and Crohn's Disease. The symptoms most commonly reported among the survey respondents included: persistent or recurrent diarrhoea (87%), rectal bleeding (85%), fatigue (79%) and painful stomach cramps (72%). Other common symptoms included joint pain (54%), weight loss (49%) and loss of appetite (40%).

With a growing UK incidence of approximately 1 in 400 population affected by Colitis or Crohn's disease, respondents reported that flare-ups of the conditions are frequent: 55% reported flare-ups every few months, while an unfortunate 9% experienced weekly problems and a further 9% reported monthly flare-ups.

The survey results underlined the fact that Colitis and Crohn's can have a significant impact on many of the activities of everyday life, with 17% reporting that their disease interfered with their ability to do their job greatly and a further 39% somewhat affected. Twenty nine per cent of respondents felt that their symptoms greatly affected leisure activities such as dining out, travel and sports, and a further 46% felt that these activities were affected to some extent.

From the communications perspective, the survey results suggest that there may be barriers to open discussion between patients and their doctors. In the UK, it appears that British patients are reticent in this respect with just 38% initiating discussions with their doctors on this topic compared with a pan-European average of 52%.

National Association for Colitis & Crohn's Disease – Press Information

British survey respondents also estimated that only 32% of doctors enquire about the way in which symptoms impact on a patient's quality of life compared with 42% in the pan-European survey. Reassuringly, when doctors do discuss the impact of symptoms on quality of life, the majority (63%) make modifications to treatment in an attempt to reduce this impact.

Commenting on the survey findings, Director of the UK National Association for Colitis and Crohn's Disease (NACC) Richard Driscoll, explained, "The aim of this survey was to develop a clearer picture of how Colitis and Crohn's disease are managed in the UK and across Europe. We needed to gain a better understanding of how patients live with these diseases and how they impact on their daily lives. The results show that the majority report that their symptoms have a significant impact on everyday life in terms of leisure activities and/or work. The survey indicates that there is considerable room for improvement in terms of open communication between patients and their doctors, particularly in the UK. Too many patients are unable face talking to their doctor about their symptoms or asking about new treatment options.

The results from the survey will be used to campaign for improved standards of care for all patients with Colitis and Crohn's, for example by increasing the number of Colitis and Crohn's Nurse Specialists, educating patients about treatment options and encouraging a positive on-going dialogue between medical professionals and their patients."

Health professionals, patients or their families seeking further information or support can contact:

**National Association for Colitis and Crohn's Disease (NACC)
4 Beaumont House, Sutton Road, St Albans, Herts. AL1 5HH**

**Daytime Information Line 0845 130 2233 NACC-in-Contact Line 0845 130 3344
Website www.nacc.org.uk**

Editor's Notes

NACC provides a valuable support network and information resource for people and families affected by Colitis and Crohn's Disease as well as raising significant funds for research. The 70 NACC Groups across the UK enable members to share information and experiences. The Daytime Information Line is available to members and non-members alike who have queries about all aspects of their disease. The NACC-in-Contact Line offers members a chance to speak to a trained volunteer with Colitis or Crohn's Disease. Membership of NACC is open to anyone who has Colitis or Crohn's Disease, their friends and families, health professionals and anyone who wishes to support the charity. Membership costs £12 in the first year, £10 thereafter.

NACC – Improving life for people affected by Colitis and Crohn's Disease

For more press information please contact:

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