



Medical charity research highlights need for Employers, Government and the NHS to improve the working lives of people with Crohn's and Colitis

Charity urges employers to make 'reasonable adjustments' for people with Crohn's and Colitis

3rd May 2011, St Albans, Herts. New research published by the medical charity **Crohn's and Colitis UK** (the working name for the registered charity, National Association for Colitis and Crohn's disease) finds that 68% of people with inflammatory bowel disease (IBD) feel that they have little or no control over their working conditions and a third receive minimal or no support from their employer.

The research entitled "*Crohn's and Colitis and Employment: From career aspirations to reality*" also included an employers' survey (private sector only) in which 66% of employer responders either admit to being totally unaware of, or only to some extent aware of, the needs of employees with IBD.

Crohn's and Colitis UK carried out the survey-based research to evaluate the long-term impact of IBD on career aspiration, opportunities and choices. Interviews were carried out with 1,906 people – 1,107 with Crohn's disease and 799 with Ulcerative Colitis. Approximately two thirds of the interviewees were in paid employment, one third were not in employment and 91 interviewees were young people aged between 16-25 years who were not yet in full-time employment.

Launching with the support of Lord Prescott on World IBD Day (Thursday, 19th May 2011), the findings of the report show serious shortfalls in employer awareness and patchy provision of reasonable adjustment, such as access to a toilet when required. The charity is seeking a Parliamentary Early Day Motion to boost understanding amongst policy makers, patients, employers, the NHS and Public Health bodies, to hold a dialogue that will raise awareness and improve support for people living and working with these conditions, and calls for increased prioritisation of quality service standards for IBD treatment and care within the NHS.

Crohn's and Colitis UK aims to increase the employment prospects for people with IBD and keep people who want to work, in work. It is hoped this report will provide the blueprint for further discussion to support all employees with chronic conditions.

Crohn's and Colitis Month – May 2011

The research highlights the fact that 78% of respondents worry about managing their symptoms (which can include urgent diarrhoea, extreme pain and fatigue) or flare-ups while at work and as a result of their condition, a third feel at risk of losing their jobs. Researchers were surprised to note just how many people with IBD soldiered in to work, despite feeling ill (80%).

Not only do employees with IBD have a high work ethic, 52% agree that they work harder to make up for any shortcomings as a result of their condition and 40% worry that their colleagues or managers think they are not “pulling their weight” at work on occasions.

The report which was supported by an educational grant from Abbott, the global health care company, further indicates that young pre-employed people with IBD find the prospect of gaining their first job a daunting challenge. A key factor since most are diagnosed between the ages of 16 and 29, at the start of their higher education or working lives.

Of the young people questioned, 69% feel that their IBD has prevented them from reaching their full educational potential, and over half have ruled out some career options. When thinking about future employment, most (82%) are worried about managing their symptoms; 66% are concerned about not being able to do their work adequately and 65% worry about employer flexibility.

Commenting on the new findings Helen Terry, Director of Patient Information and Support at Crohn's and Colitis UK, explains, “The Report shows a clear need to provide support for young people and improve the quality of careers guidance. Balancing the needs for many of the 250,000 people living with IBD in the UK to improve their working conditions can have a positive impact on individuals and on their work situation. We are asking employers to make “reasonable adjustments” such as easy access to toilets, time for doctor/hospital appointments separate from their holiday allowance and flexible working, which can make all the difference to those either in work or looking for work. Clearly other factors such as the prioritisation of the *IBD Service Standards* for patient treatment and care must also be taken into account.”

To receive a free copy of the Report or the Summary Findings please email Crohn's and Colitis UK info@crohnsandcolitis.org.uk. If you would like to bring the findings of the Report to the attention of your local MP or would like to attend the Report launch event on 19th May please email your request to info@crohnsandcolitis.org.uk. **ENDS**

Crohn's and Colitis Month – May 2011

Press Contacts

For exclusive patient case studies in your region and further information on this press release or for an interview request, please contact Sarah Rogers or Emily Dean at the Crohn's and Colitis UK Press Office on 01252 790507 or email on sarah@healthcare-pr.co.uk and emily@healthcare-pr.co.uk

Crohn's and Colitis UK Background Information

Crohn's and Colitis UK (formerly the National Association for Colitis and Crohn's Disease) 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. Since 1984, members have raised over £5 million and more than 100 research awards have been made to hospitals and universities throughout the United Kingdom. The 70 local Crohn's and Colitis UK Groups across the UK enable its 31,000 members to meet other people who have these illnesses and share information and experiences.

Crohn's and Colitis UK also campaigns for better healthcare services and seeks to raise awareness of these illnesses and their impact on people's lives. Crohn's and Colitis UK is a partner in the UK national IBD Audit Project and has been leading the IBD Standards Group developing national standards for NHS IBD Services.

The Crohn's and Colitis UK Information Line (daytime) 0845 130 2233 is available to members and non-members alike who have queries about all aspects of their disease. The Crohn's and Colitis UK-in-Contact Line (afternoons and evenings) offers people a chance to speak to a trained volunteer who has Colitis or Crohn's Disease. There is a special Parent-to-Parent Helpline and support available for people claiming Disability Benefit.

Membership of Crohn's and Colitis UK 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 per year and the charity offers free membership to 16-18 year olds.

What Is Inflammatory Bowel Disease (IBD)?

Ulcerative Colitis and Crohn's Disease are the main conditions described as IBD. They 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 more or less equal numbers. The overall prevalence of IBD in the UK is estimated to be 240,000, approximately 400 patients per 100,000 population.

It is important to note that IBD means *Inflammatory Bowel Disease*; this is not the same as IBS, which means *Irritable Bowel Syndrome*. The latter is a functional disorder of the digestive system and is treated in a completely different way. Some IBD patients may also have IBS.

For a breakdown on disease-specific statistics or more information on the individual conditions please contact the Crohn's and Colitis UK Press Office on 01252 790507.

Crohn's and Colitis Month – May 2011

Clinical effects

The key effects of the disease are inflammation and ulceration in the colon and rectum (Ulcerative Colitis) or anywhere in the gastrointestinal tract (Crohn's Disease). Crohn's Disease can follow either of two patterns – structuring disease (narrowing of the

intestine causing obstruction) or fistulising disease (where the disease creates holes in the bowel wall that allow the faecal contents to leak out).

Both conditions can produce symptoms of urgency, diarrhoea, pain, profound fatigue and anaemia, with, for some patients, associated inflammation of the joints, skin, liver or eyes. Malnutrition and weight loss are common with patients often altering their eating habits to alleviate symptoms. When diagnosed in childhood (about 25% of all cases) the disease is often more severe than if presenting in adulthood with major consequences on life-long morbidity.

IBD follows an unpredictable relapsing and remitting course with significant variation in the pattern and complexity of the symptoms both between patients and in the individual patient at different times in his or her illness.

Treatment

Aminosalicylates (5-ASA), corticosteroids and immunosuppressive drugs are the mainstay of medical management for inducing and maintaining remission. They suppress the symptomatic effects, but the extent to which they alter the natural course of the disease remains unclear.²¹ Thirty per cent of patients will fail to respond to these drugs or be intolerant of them and these patients may then be considered for anti-TNF biological therapies or surgery. Between 50% and 70% of patients with Crohn's Disease will undergo surgery within 5 years of diagnosis.

Psycho-social effects

Education, employment, personal relationships, social and family life are all disrupted by the unpredictable occurrence of flare-ups. The frequent and urgent need for the toilet, together with loss of sleep and the invisible symptoms of pain and continual or profound fatigue, can severely affect self-esteem and social functioning, particularly among the young and newly-diagnosed. For understandable reasons, a proportion of patients normalise an unnecessarily limited pattern of life either due to inadequate control of symptoms from poor medical management or because of the loss of self-esteem and deep anxiety about losing bowel control if they venture too far from familiar environments.

Causation

The causes of both Crohn's Disease and Ulcerative Colitis remain unknown. There is a genetic predisposition which increases the risk of IBD about tenfold in first degree relatives of an IBD patient and which probably determines the pattern and severity of the disease in any individual patient. Much research is focused on understanding the role of bacteria in the gut and the many different parts of the immune system's response to external triggers. It seems quite likely that the trigger for the disease varies between individuals.

Symptoms

IBD can produce symptoms of urgency, diarrhoea, pain, profound fatigue and anaemia, with, for some patients, associated inflammation of the joints, skin, liver or eyes. Malnutrition and weight loss are common with patients often altering their eating habits to alleviate symptoms.

Crohn's and Colitis Month – May 2011

Crohn's and Colitis UK Corporate Support Scheme

Crohn's and Colitis UK (NACC) operates a formal Corporate Support Scheme. Corporate Supporters can make an annual donation at three levels – Gold £20,000, Silver £10,000 and Bronze £5,000. The charity normally agrees with each company how half of their donation will be applied; the other half is made as an unrestricted grant to support the charity's work. Abbott is a Gold level Corporate Supporter of Crohn's and Colitis UK

This research project is supported by an educational grant from Abbott that is unrelated to its corporate support status. The grant is being delivered through service provision of independent research and media support, and not as a monetary gift to the charity.

For further information: Crohn's and Colitis UK (NACC) has a policy statement of relations with the Pharmaceutical Industry available for download

http://www.crohnsandcolitis.org.uk/downloads/NACC_Pharmaceutical_Relationships_Policy_2011.pdf

Crohn's and Colitis UK, 4 Beaumont House, Sutton Road, St Albans, Herts, AL1 5HH

Administration Tel: 01727 830038; Information Line 0845 130 2233

Website: www.CrohnsAndColitis.org.uk

Registered Charity in England and Wales. No. 1117148

Registered Charity in Scotland No. SC038632