



European Federation of Crohn's and Ulcerative Colitis Associations - EFCCA

EMBARGOED UNTIL 18 OCTOBER 2005
12:00 CEST / 6:00 AM EDT

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FIRST-EVER EFCCA PAN-EUROPEAN SURVEY OF PATIENTS WITH IBD REVEALS DISPARITY BETWEEN REPORTED TREATMENT SATISFACTION AND ACTUAL IMPROVEMENT IN SYMPTOMS

Leading European Coalition of IBD Patient Organizations Encourages Patients to Seek Best Treatment Options

COPENHAGEN, Denmark, 18 October 2005 – Results from the first-ever pan-European survey of more than 5,000 patients with inflammatory bowel disease (IBD) reveal more needs to be done to manage the painful and reportedly embarrassing symptoms of their disorders. While most patients reported some level of satisfaction with their current treatment, a large number also admitted their symptoms continue to adversely affect their daily lives. A similar discrepancy was unveiled with patients that underwent surgery to treat IBD, yet many continue to suffer symptoms. Nearly all patients would rather try a new therapy than face surgery. The survey was initiated by the European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA), and results were unveiled today at the 13th United European Gastroenterology Week (UEGW) meeting.

Similar results were seen among surveyed patients with ulcerative colitis (UC) and Crohn's disease (CD), the two debilitating conditions that comprise IBD. A majority of patients (76 percent UC, 76 percent CD) reported satisfaction with their current treatment medications, although most also reported their symptoms continue to greatly affect their ability to enjoy leisure activities (73 percent UC and 78 percent CD) and perform in their work (66 percent UC and 72 percent CD). Approximately two-thirds of patients (both CD and UC) rated their quality of life after surgery as greatly improved. However, a large number of patients (43 percent UC and 69 percent CD) still had a recurrence of symptoms with many reporting serious complications after surgery (32 percent UC and 26 percent CD).

“Patients with IBD should not suffer in silence and allow their symptoms to control their daily lives,” said Rod Mitchell, chairman of the EFCCA. “Help is always available, and we encourage patients to speak openly with their doctors about their symptoms and where necessary ask about other options and treatments, including the newer biological agents which may be suitable for some patients.”

A large majority (86 percent) of patients reported they would rather try a new therapy than face surgery. The latest advances for the treatment of IBD include biologic therapy. Infliximab, currently the only biologic approved for CD has also demonstrated efficacy in the treatment of UC. More than three-quarters (77 percent) of surveyed patients with CD treated with infliximab reported their symptoms improved after treatment.

Other Key Survey Findings:

- Most patients (60 percent UC and 47 percent CD) experience symptoms for one year before seeing a gastroenterologist; some (17 percent UC, 24 percent CD) experienced symptoms for over 5 years before seeing a gastroenterologist.
- Only 52 percent of patients with UC and 59 percent of patients with CD initiate a discussion with their physician about the impact of symptoms on their quality of life.
- Nearly 58 percent of patients with CD have undergone surgery to treat their disease, yet 69 percent of patients with CD have had a recurrence of symptoms post-surgery.
- Among the more common therapies being currently prescribed to respondents were:
 - immunomodulators (19 percent UC and 31 percent CD)
 - steroids (19 percent UC and 19 percent CD)
 - anti-inflammatories/5-amino-salicylic acid (5-ASA) therapies (66 percent UC and 48 percent CD)

About the Survey

European national IBD patient organizations affiliated with the EFCCA were invited to participate in a survey of their members. Seven organizations participated, representing Denmark, Italy, the Netherlands, Spain, Switzerland, the United Kingdom and Portugal. Survey questionnaires were distributed to 12,200 members of these organizations; 5,636 responses were tabulated and analyzed by the FFG, an independent opinion research institute based in Germany. The survey was funded with support from Schering-Plough Corporation.

About IBD

It is estimated that more than one million Europeans suffer from Crohn’s disease (CD) and/or ulcerative colitis (UC), which are collectively known as inflammatory bowel disease (IBD) and cause inflammation

and sores (ulcers) in the digestive tract and large intestine, respectively. Also known as colitis or proctitis, UC typically occurs in the rectum and lower part of the colon, but it may affect the entire colon. CD usually occurs along the walls of the small intestine and/or colon, but can also affect other areas of the digestive tract between the mouth and anus. Symptoms of IBD may include abdominal pain, diarrhea, loss of appetite, rectal bleeding, weight loss, fever, joint pain, fatigue, skin tags, and sores around the anal area. The number affected with IBD continues to rise, especially among young people between the ages of 15 and 35, who are the most commonly diagnosed.

About the EFCCA

Established in 1993, the EFCCA's mission is to improve the well being of patients with IBD and their partners and families through: working with and for the EFCCA Member National Associations and others throughout all of Europe; facilitating the exchange of information and the promotion of cross-frontier activities; effecting regular contact with the European authorities, doctors, health professionals and organizations and with others worldwide; and the encouragement of scientific research into IBD causes and treatment. Over the past decade, often with EFCCA support and advice, national self-help associations have been set up in Eastern Europe, often with local support of gastroenterologists and other health professionals. EFCCA membership now includes 22 European national Crohn's and colitis patient associations.

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