

JOIN
THE
FIGHT
AGAINST
IBD

PRESS KIT

February 15th BCN



EFCCA calls for increased healthcare access, a wider array of treatment options and enhanced care protocols for people living with inflammatory bowel diseases

Results of European-wide survey show worrying figures

Barcelona, Spain. Feb. 15 – Today the European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA) presents the full results of the European wide IMPACT survey – which aims to show the true impact of inflammatory bowel diseases (IBD) on patients' life, covering not only medical issues but also additional aspects such as quality of life, education, employment, relationships and disability.

EFCCA represents 103,000 active members in 27 national patients' associations of Crohn's disease and ulcerative colitis. 24 European countries participated in the survey with a total of **4990 responses** analyzed to date. It revealed that whilst access to specialist care is usually good and most IBD patients receive a timely final diagnosis, there are still around 18 % of patients who wait for the diagnosis over 5 years. This can be a period of uncertainty, significant life impact, morbidity, and distress - and could create a clinical risk as **64 % may need emergency care BEFORE the diagnosis.**

"The main findings of the survey show that the impact of IBD in our lives is still immense and at an unacceptable level, said Marco Greco, President of EFCCA. "EFCCA calls on patient associations, healthcare professionals and policy makers to address these finding in order to improve better access to treatment, provide a wider array of treatment options with enhanced care protocols, as well as equal opportunities for people living with IBD" he added.

The IMPACT Survey shows that hospital admission in IBD patients is **extremely high at 85%**, representing significant morbidity, and demand on health services. Access to biological therapy is becoming more established, although a minority of patients take this treatment. Worryingly, the majority of patients have used corticosteroids with a high proportion experiencing side-effects, and almost all our concerned about long-term effects.

Responses concerning access to healthcare showed that although specialised healthcare professionals are present, a quarter of people with IBD feel they **do not have adequate access** to them. Moreover, 53% of respondents feel that they were not able to appropriately communicate with their care provider.

Concerning the impact on relationships, IBD has a significant negative social effect and an alarming proportion of people **(40 %) claimed that it prevented or caused the end of intimate relationships.** However, meeting others with a similar condition, or becoming part in patients' organizations creates optimism. **63 %** of respondents felt that membership of a patients' organization has a **beneficial impact on life** as a whole.



JOIN THE FIGHT AGAINST IBD



Most IBD patients (74 %) have taken time off work in the last year due to IBD – most startling, over a quarter of respondents had been absent from work for over 25 days in the last year. Disease severity and ability to work seem to correlate. The majority feels stressed or pressured about taking time off. **25% of IBD patients have received complaints or unfair comments at work, or suffered discrimination.**

IMPACT was supported by an educational grant from Abbott, the global healthcare company.

For more information please contact Isabella Haaf, communication manager at bella.haaf@efcca.org or tel: +34 606849937.

About EFCCA

EFCCA is an umbrella association representing 27 patients associations across 26 European countries with more than 100,000 members. EFCCA aims to work to improve life for people with ulcerative colitis or Crohn's disease (together called Inflammatory Bowel Disease, or IBD), at European level. Its main objective is to improve the well-being, quality of life and quality of care of people with IBD of all ages, working both at European level and alongside member associations; to improve public awareness of IBD and the concerns of European patients; to encourage research into the disease; and to promote equality of opportunity for people affected by IBD.

