



International Foundation For Functional Gastrointestinal Disorders

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March 12, 2012

Joe V. Selby, M.D., M.P.H.
Executive Director
PCORI
1701 Pennsylvania Ave. NW, Suite 300
Washington, DC 20006

Dear Dr. Selby,

We applaud the efforts of PCORI and have been following the development and progress of the research agenda.

The digestive disease community is one that we hope you will consider in your priorities moving forward. Twenty percent of the United States population suffers from a functional gastrointestinal (GI) disorder or motility disorder. Many of these people have multiple or overlapping conditions. This is a population that will benefit from research in all of the areas that have been outlined.

Most notably: Comparison of prevention, diagnosis and treatment options and Improving health care systems.

The International Foundation for Functional Gastrointestinal Disorders has been focusing on research that incorporates the patient perspective for over a decade. Of the dozens of functional GI and motility disorders, irritable bowel syndrome (IBS) is the most studied and among the most prevalent. It effectively serves as representative of the patient experience across these conditions. We first conducted "IBS in the Real World Survey" in 2002. As patient advocates we had often thought that the severity, frequency, and pain associated with IBS symptoms were underestimated, making it difficult for the treatment needs of this chronic disease to be fairly evaluated. The findings of this study confirmed our concerns. The survey findings painted a distressing portrait of the disease and one that deserves intensified research attention to identify safe and effective treatments.

In 2009 IFFGD published "IBS Patients: Their illness experience and unmet needs," (also peer review: Drossman DA et al. International survey of patients with IBS: Symptom features and their severity, health status, treatments and risk taking to achieve clinical benefit. *J Clin Gastroenterol*. 2008 Jul;43(6):541-50). This survey of 1,966 patients once again captures the severity and quality of life issues that IBS patients face. It also goes further to look at expectations on symptom improvement, satisfaction with treatment and evaluating risk associated with medication.

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I have enclosed a print copy of each of the surveys mentioned above for your reference.

Almost everyone is touched by a digestive disorder or disease in one way or another, if not personally then perhaps by a family member or friend. They are disorders that are often difficult to talk about and continue to be hidden in society. If we can be of any assistance in any way please let us know.

Sincerely,

A handwritten signature in cursive script, appearing to read "Nancy J. Norton". The signature is written in black ink and is positioned above the printed name.

Nancy J. Norton