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December 21, 2009

The Honorable John McCain
241 Russell Senate Office Building
Washington, DC 20510

Dear Senator McCain:

Thank you for your continued leadership on healthcare issues.

As the President and Founder of the International Foundation for Functional Gastrointestinal Disorders (IFFGD), I write you today on behalf of the millions of Americans that suffer from Irritable Bowel Syndrome (IBS) regarding your vocal opposition to a congressionally directed spending project at Cedars-Sinai Medical Center designed to help serve IBS patients. IFFGD is interested in helping IBS patients; we are in no way connected to the federal project at issue.

IFFGD is a nonprofit patient-driven organization dedicated to assisting individuals affected by functional gastrointestinal (GI) disorders by providing education and support, and advancing critical research.

IBS is a disorder of neurological and gastrointestinal functioning. It is characterized by the presence of chronic pain or discomfort in the abdomen, which is the overarching symptom, related to changes in bowel/intestinal function. Other GI symptoms such as nausea or heartburn, and non-GI symptoms such as sleep disturbances, headache, and joint or muscle pain may often occur. There is no cure and few treatments, most of which are marginally effective. The many individuals with moderate to severe IBS struggle with symptoms that significantly impair their physical, emotional, economic, and social well-being.

IFFGD appreciates your efforts to rein in spending and promote responsible government. However, by singling out this IBS project during the Senate's consideration of the FY 2010 omnibus appropriations package and disparaging it as wasteful, you inadvertently send a message to the IBS community that federal efforts to address the suffering of IBS patients are somehow less serious than similar efforts focused on other conditions. Due to the lack of awareness and understanding about IBS, many disabled or severely hindered patients routinely face obstacles that stem from a misinformed perception that their symptoms are either fleeting or trivial. "Irritable bowel syndrome" may sound funny to some, but to those affected by the disorder it is no joke. Public referencing IBS in jest only

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adds to the negative perceptions surrounding the condition and exacerbates the challenges IBS patients have to overcome to find adequate care and achieve a meaningful quality of life.

Regarding your interest in the appropriate use of federal funds, you may be interested to know that the lack of accurate information and awareness about IBS actually adds to the expense of diagnosis and treatment, and cost to businesses and taxpayers. Many IBS patients go for years seeking adequate care and undergo unnecessary tests and procedures, including surgeries, as their physicians search for the cause of their symptoms. Misdiagnosis and under-recognition by patients and physicians leads to higher medical costs and unnecessary suffering. Furthermore, IBS is a leading cause of work absenteeism and presenteeism, an added financial burden to employees and employers alike.

IBS affects up to 15% of the population and accounts for roughly 40% of all referrals to gastroenterologists. A high incidence has been noted in combat veterans and is strongly correlated with "Gulf War Syndrome." Yet despite how common and burdensome IBS is, relatively little is known about causes and prevention; patients have limited treatment options.

We are encouraged that over the past few decades, research has begun to advance the understanding of mechanisms underlying IBS. It is through research that hope lies for improved medical care and delivery.

Moving forward, we hope to work with you to help raise awareness of IBS in a positive manner for the benefit of IBS patients across the country. Better education and awareness will help improve understanding surrounding IBS and generate constructive dialogue and actions. In addition, we hope to work with you on important legislative efforts to advance IBS research in a responsible manner, and improve the availability and quality of treatment options for IBS patients.

Enclosed is an IBS Fact Sheet we have prepared for you along with two recent publications regarding IBS and patients' unmet needs. We trust you will find this informative as you seek to respond to public needs.

Thank you for your time, your attentiveness to our concerns, and your consideration of our request to work toward improving health care options and delivery for those affected by IBS. If you have any questions or require any additional information, please feel free to contact us.

Sincerely,

Nancy J. Norton
President
Encl.