# Clinical Trials Community eNewsletter



### Spring 2019

Welcome to the Crohn's & Colitis Foundation's Clinical Trials Community eNewsletter. This newsletter will be sent on a quarterly basis to keep you up to date on research happenings in inflammatory bowel diseases (IBD).



## The Cycle of Presenteeism and Working While Sick

Have you ever gone to work feeling sick? Do you feel the need to be at work because of the fear that your disease could hinder your career? This type of need is known as presenteeism and was studied by researchers at the University of Manitoba. They were interested in assessing the connection between quality of life and reduced work efficiency in those living with inflammatory bowel diseases (IBD). The results of this study are summarized in our latest research update blog titled "Association Between IBD Disability and Reduced Work Productivity (Presenteeism): A Population-Based Study in Manitoba, Canada" by Nataly Shtraizent, PhD, research manager.

The term presenteeism explains the behavior of individuals who battle a chronic illness and believe they must go to work even when not feeling well. These individuals may experience the following:

- 1. Concerns of feeling behind in their work
- 2. A need to feel irreplaceable
- 3. Overworking to counteract when their disease acts up Click <u>here</u> to read about the results of this study and to learn more.

### Visit our New Resources for Professionals Page!

For professionals interested in predicting their enrollment rates for clinical trials, we now have a new clinical trial predictor tool. This tool is housed within our Clinical Trials Community. Click here to learn more about this tool and how it operates.

## Improve Your Research Vocabulary with our Word of the Quarter!

#### **Adverse Event**

This type of event happens when an unforeseen obstacle occurs during the clinical trial. It may or may not be in relation to the study drug being taken. Symptoms can range from mild to moderate or severe. During a clinical trial, a patient will be asked to document any adverse events they experience and then discuss them with their doctor.

www.crohnscolitisfoundation.org

## Connect with Clinical Trial Ambassadors

This year at local Foundation events, newly trained ambassadors will be available to answer questions relating to their participation and involvement with clinical trials. If you would like to be matched with an ambassador to speak about their clinical trial experiences through our Power of Two program, reach out to us at <a href="mailto:powerof2@crohnscolitisfoundation.org">powerof2@crohnscolitisfoundation.org</a>.



## **Meet Ambassador Volunteer Jennifer Annis**



Jennifer is from Indiana. Her son is 11 years old and suffers with Crohn's disease. Jennifer is not only a caregiver to a child with this disease but also a Crohn's disease patient herself. After her son was diagnosed and began treatment, they were approached about having him join in a clinical trial. Click here to read more about their story.

If you have questions or concerns about clinical trials and want to learn more, we offer a collection of infographics. Click here to view.

Learn more about pediatric clinical trials.

#### **Comment on the Future of IBD Research**

The Foundation is dedicated to accelerating research to drive the continuum from new discovery to optimal care. To accomplish this, every five years the Foundation convenes leading researchers and patient/caregiver stakeholders to review the current state of research and identify new priorities in inflammatory bowel diseases (IBD) research. The final product is known as the *Challenges in IBD Research* publication.

We are pleased to share the draft 2019 *Challenges in IBD Research* manuscript and announce our request for public comment on the draft. The manuscript can be viewed <u>here</u>. In it, five focus areas were identified to address unmet needs in IBD research:

- 1. Preclinical human IBD mechanisms
- 2. Environmental triggers
- 3. Novel technologies
- 4. Precision medicine
- 5. Pragmatic clinical research

Public comment on *Challenges in IBD Research* will be open from January 28 through February 25, 2019, and can be submitted electronically here.

We welcome comments from all members of the IBD community; however, *Challenges in IBD Research* is written by research professionals using technical terminology, and certain concepts described may require a medical or scientific background to fully understand. The authors will review all submitted comments and recommendations prior to finalizing the document.

Following this public comment process, the final document will be submitted for publication in *Inflammatory Bowel Diseases®*, the official journal of the Crohn's & Colitis Foundation. Once published, *Challenges in IBD Research* will be made publicly available via the Foundation's website.

www.crohnscolitisfoundation.org