

IBD Digest

Welcome to UPMC's inflammatory bowel disease and behavioral health study!

Thank you for participating in the UPMC Inflammatory Bowel Disease (IBD) and Behavioral Health Research Study! Our goal is to better understand how specialty medical homes—like the UPMC clinic you visit—can best support the overall health and well-being of people with IBD.

The primary goal of the study is to look at how attending either in-person or telemedicine appointments impact patients' IBD and behavioral health symptoms. We will also look at which patients may benefit the most from each approach. By participating, you are helping us acquire new knowledge and information about IBD. This information could lead to improvements for IBD patients and their families, clinicians, and health care payers.

UPMC Presbyterian is one of three sites involved in this study. Participants are also enrolling at Mount Sinai Hospital in New York and Cleveland Clinic in Ohio. The goal is to enroll 990 patients with IBD across the three sites.

We will send you newsletters twice a year to keep you updated on the study's progress. These newsletters will give you a chance to learn more about members of UPMC's IBD clinic and research study staff, stay up to date on community resources, get access to recipes and helpful tips for managing IBD, and find out what we are learning from the study.

Thank you again for agreeing to be part of this important study. With your help, we hope to enhance the care experiences and outcomes of those living with IBD.

STUDY PROGRESS

As of March 13, 2020,
we have enrolled

141

participants across the
three study locations!

We are 14 percent of the
way to our goal.

REMEMBER!

All participants are asked
to complete a series of
questionnaires at three points:

- Upon enrolling in the study
- Six months after enrolling
- One year after enrolling

You will be paid \$20 each for the
initial and six-month
questionnaires, and \$40 for the
final questionnaire.



Meet the principal investigators

Every study has a principal investigator (PI) who is responsible for making sure everything goes smoothly. It's the PI's job to address any questions or concerns that might come up and ensure that the study's findings are effectively communicated.

We have two PIs. Let's get to know them. **See page 2.**



Eva Szigethy

MD, PhD: Co-director, UPMC IBD Total Care subspecialty medical home; professor of psychiatry and medicine, University of Pittsburgh; director, behavioral health within the Chief Medical and Scientific Office, UPMC

What do you like best about conducting research?

My favorite part is coming up with the research questions based on things I observe as a clinician. For example, I see

daily how helpful behavioral techniques can be in reducing gastrointestinal symptoms, and a well-designed study allows you to understand the degree of the improvement.

What's your favorite thing to do in your spare time?

I row on a high-performance master's crew team. There is no more invigorating way to start the day than to watch the sun rise from seat six of a women's eight boat.

What's the most rewarding part of your job?

My favorite part of my job is helping patients overcome challenges and attain their goals and dreams.

What's one thing about you that people might be surprised to learn?

I speak Hungarian fluently. When I was on junior faculty at Boston Children's Hospital, I translated a cognitive behavioral therapy (CBT) manual into Hungarian with the help of my mother and spent a week in Budapest training 62 child psychiatrists in the country on using CBT to treat depression in adolescents.

Community resources

If you are looking to engage with your local IBD community, the Crohn's and Colitis Foundation (CCF) has a western Pennsylvania/West Virginia chapter with events, support groups, and resources to help you learn more about living with IBD. You can learn more about the chapter at crohnscolitisfoundation.org/chapters/wpawv.

Upcoming events:

Pittsburgh Virtual Take Steps Walk: June 20 at noon
Join a team and take a walk around your neighborhood to help raise funds for the Crohn's and Colitis Foundation's research efforts.

Spin4 Crohn's and Colitis Cures: September 26 at 1 p.m.
Work up a sweat during a two-hour spin bike session (as an individual or with up to three friends) to raise money for the Crohn's and Colitis Foundation.

Night of Steel: November 7 at 6 p.m.
Test your knowledge of local info and enjoy Pittsburgh-themed food at the Crohn's and Colitis Foundation's third-annual Night of Steel at Heinz Field.



Laurie Keefer

PhD: Professor of medicine and psychiatry, Icahn School of Medicine at Mount Sinai

What do you like best about conducting research?

Currently, I think my favorite parts are twofold: study design and facilitating question generation by new researchers. The PCORI project is particularly exciting to me because it challenges me to combine my two worlds: science and practice.

I have been forced to think both carefully and flexibly about how to do good and meaningful research in a way that translates into real-world settings.

What's your favorite thing to do in your spare time?

What spare time? I have two grade-school children who keep me pretty busy. I have a long commute every day, so I also have quite the podcast/audiobook collection. I also play the piano.

What's the most rewarding part of your job?

There is such a reward for me in human connection, and I have such appreciation for my patients who are willing to courageously work on improving their lives despite what are often insurmountable challenges. The nice thing about being both a clinician and a scientist is that I have a first-hand view of the limitations patients face when navigating the health care system and have a "seat at the table" to change things, even if it is sometimes slow.

What's one thing about you that people would be surprised to learn?

I am actually pretty shy, but my two top character strengths are curiosity and optimism. These allow me to really push forward for the causes I care about!

World IBD Day

May 19 is World IBD Day, an international effort to bring awareness to those who have Crohn's disease and colitis. Wear or display your purple IBD awareness ribbon to help spread the word. You can learn more at worldibdday.org.



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DISCLAIMER: All statements in this report, including its findings and conclusions, are solely those of the authors and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute (PCORI), its Board of Governors or Methodology Committee.

RECIPE

Low-Fiber Trail Mix

Makes 8 servings (serving suggestion: ½ cup)

Ingredients:

- ½ cup cashews, raw
- 1 cup mini pretzels
- 1 cup Rice Chex
- 1 cup Chocolate Chex
- ½ cup chocolate candy pieces

Directions:

1. Mix all ingredients in a bowl.
2. Enjoy!

Recipe developed by Therezia Alchoufete, MS, RD, LSN,
Clinical Dietitian Specialist, UPMC Total Care- IBD



Contact

If you have any questions, please contact a member of the research team at 412-208-5235 or email us at IBDStudy@upmc.edu. We can help you:

Address concerns
about your Vincent
Payment Card.

Update your
contact
information.

Resolve issues
you are having
with the Brain
Manager app.

Schedule a time to
complete your
follow-up
questionnaires.

