

Take charge of your health today. Be informed. Be involved.



ESTHER BUSH

IBD

This month, the "Take Charge of Your Health Today" page focuses on inflammatory bowel disease (IBD) and a new care model for this set of diseases. Vianca Masucci, health advocate, and Esther L. Bush, president and CEO, both of the Urban League of Greater Pittsburgh, exchanged ideas on this topic.

VM: Good afternoon, Ms. Bush. This month we're talking about IBD. IBD is a general term for a variety of diseases that cause discomfort in the intestine. These types of diseases have become more commonly reported in the Black community over the past few decades.

EB: That makes sense, Vianca. As you were talking, I thought of all of people I know who have some kind of IBD, and I realized that I know quite a few. I don't remember talking much about these before, say, a decade ago. There has been a greater awareness of these diseases in the Black communities. I don't know if that's because more people are getting them or because more people are talking about them.

VM: That's an interesting point, Ms. Bush. I don't think that researchers have figured that out either. One of the issues with IBD is that people don't like to talk about the symptoms because they're very personal. As Dr. Regueiro says in the overview, people don't like talking about their bowels. But these symptoms can have a big effect on an individual's life. The symptoms range from pain to abnormal bowel habits to symptoms outside of the bowels like arthritis. IBD can make it hard for a person to rely on his or her body. It can be a very stressful disease—and that stress affects both physical and mental health.

EB: It's complex. I imagine that someone suffering from IBD would need a team of professionals to help with all the different parts of the disease. That's why I'm very impressed with Dr. Regueiro's research. He has found that patients living with IBD have better health outcomes when their care is coordinated by one person and is provided in one location. Patients don't have to run around town, going to appointments to get help for the different effects of these diseases, like the physical, mental and social. Dr. Regueiro's care model allows for the patient to be treated for everything in one place. This whole-patient care model has been proven to work better for patients with IBD.

VM: Isn't that amazing? The approach is so modern. I love to see research in action and changing care for the better.

EB: Yes, I'm happy to know that care is getting better for those who suffer from IBD. If you are one of those folks living with IBD, don't be discouraged if you've had a hard time finding good care in the past. Things are changing; you can find better care. If you have symptoms of IBD but you've never gotten care, now is the time to seek it out. IBD is not embarrassing; it's a disease, and there are things that can help it.

VM: I'd also like to say that participating in research is especially important right now. As Dr. Regueiro mentioned, the IBD research is now focusing on how IBD affects different populations and how to treat these differences. One of the reasons that IBD may be becoming more commonly reported in the Black community is because the symptoms may present differently in African Americans than in other populations. But researchers cannot find out if and how IBD is different in the African American population unless there are African Americans participating in the IBD research studies.

EB: Absolutely, Vianca. I encourage all those reading to learn more about the IBD research studies featured on this page. Participating in health care research can improve care.

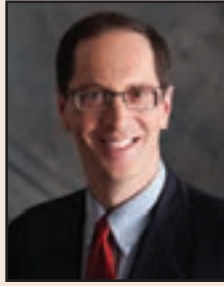
VM: Thanks for your time, Ms. Bush. I look forward to hearing your thoughts on next month's topic, which is family planning.

Inflammatory Bowel Disease

People who have inflammatory bowel disease (IBD) know well its physical effects. But physical symptoms are not the only effects of IBD. IBD sufferers' entire lives are affected, so they often end up seeing many different doctors. A new model of medical care is being used to help people with IBD cope with all of its effects.

Crohn's disease and ulcerative colitis are the main inflammatory bowel diseases that are caused by an abnormal response by the body's immune system against the gastrointestinal tract. Crohn's disease is an inflammation of the lining of the digestive tract. It can cause severe diarrhea, stomach pain and cramping, bleeding, weight loss and malnutrition. Ulcerative colitis is a chronic disease of the colon. The lining of the colon becomes inflamed and develops tiny open sores, or ulcers, that produce pus and mucus. It causes stomach pain, diarrhea, bleeding, weight loss and fatigue. No one knows exactly what causes either disease. Complications from both diseases can lead to hospitalization and surgery. Medications can be aggressive and may have side effects but often help to put people in remission. IBD usually strikes people between the ages of 15-35.

Miguel D. Regueiro, MD, professor of medicine and of clinical and translational science, University of Pittsburgh School of Medicine, says that IBD also carries a stigma. "People generally don't like talking about their bowels," he says. "People often live with IBD silently and don't talk to family or friends about it. It can make them nervous about being out in public. The stigma can cause symptoms of depression and anxiety."



MIGUEL D. REGUEIRO, MD

Dr. Regueiro is also the codirector of UPMC Total Care-IBD, the nation's first patient-centered medical home for people with IBD. Dr. Regueiro's research has shown that coordinating the care and managing the symptoms of IBD can be a time-consuming, disjointed experience for both patients and doctors. The idea behind patient-centered medical homes is to have all health care coordinated by one person and one team, often provided in the same location (sometimes even in the same day). Dr. Regueiro's research has demonstrated that patient-centered medical homes improve the patient experience, enhance the quality of health care and decrease costs for patients and insurers.

"In the IBD medical home model, the gastroenterologist coordinates the whole-person care," says Dr. Regueiro. "At the beginning of a visit, we'll ask patients a set of questions that include what their three top problems are and what they want to get out of the visit. For example, a patient tells us she had a hard time paying for the bus to come to clinic. She has a lot of stress and bone pain. The gastroenterologist sees her for the IBD and then helps her tackle her other top concerns. The patient meets with the social worker or psychiatrist on our team for the stress. She also sees the dietitian, the surgeon and a pain specialist—all in one visit. After that, rather than bring her back for multiple separate visits, we're now using telemedicine [checking in using technology] and remote monitoring so that she doesn't need to come into clinic as often."

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In addition to the medical home

World-renowned athlete scores big against Crohn's

(BPT)—For world-renowned soccer player Brandi Chastain, having a game plan in place to achieve goals was second nature. Chastain is a former member of the United States women's national soccer team and a retired professional soccer player who was recently elected to the U.S. Soccer Hall of Fame. When Chastain's now 10-year-old son was diagnosed with Crohn's disease, she had to tackle a different type of plan. Chastain has partnered with Abbie on My IBD Game Plan, a program designed to help people living with Crohn's disease and ulcerative colitis, the two most common forms of inflammatory bowel disease (IBD), create a plan to help manage everyday life with these diseases.

EVA SZIGETHY, PHD, MD, MS

The program encourages people living with IBD, and their caregivers, to proactively work with their doctors and support team to take control and manage the symptoms of these diseases. Program resources can be found at CrohnsandColitis.com.

"Being on a team is something that has always been very important to me, and when my son was diagnosed with Crohn's disease, I found myself on a new team," said Chastain. "There are 1.6 million Americans who live with IBD daily, and CrohnsandColitis.com is a great resource for them to be able to find information, to ask questions and to talk to their doctor about an appropriate treatment plan."

As many as 70,000 new cases of IBD are diagnosed in the U.S. each year. Crohn's disease and ulcerative colitis can be serious diseases that can get worse over time, with symptoms that may change in severity or change over the course of one's life and it is important to talk to a doctor about any change in symptoms and appropriate treatment options.

People living with IBD usually go through periods of remission, meaning few or no symptoms, alternating with periods of more active disease symptoms.

Want to understand more about IBD?

IBD, including Crohn's disease and ulcerative colitis, are chronic, disabling conditions. These diseases affect up to 2 million people in the United States. There are many things about IBD causes and treatment that remain unknown. However, the causes are likely a combination of both people's genetic information and environmental factors. Some estimates show that IBD costs the United States

\$6.3 billion in direct medical costs each year and another \$3.6 billion in loss of productivity. IBD is primarily diagnosed in the early decades of life in both men and women. Patients diagnosed with IBD require lifelong specialized care, medical therapies and sometimes surgeries. It is an extremely complex disease. Researchers and physicians do not yet have a widely accepted strategy to understand the sever-

ity of the disease over time or to guide the best treatment decisions.

Participating in research is critical to help researchers understand more about IBD. UPMC has an Inflammatory Bowel Disease Center and an IBD Research Registry. If you are interested in joining or learning more about IBD research studies, go to www.pittplusme.org and search the IBD Studies page.



Brandi Chastain on July 10, 1999, in her iconic pose, celebrating Team USA's victory in the Women's World Cup. (AP Photo/The San Francisco Examiner, Lacy Atkins, File)

Common symptoms of Crohn's disease and ulcerative colitis include diarrhea, abdominal pain or cramping and rectal bleeding. There is no cure for Crohn's disease or ulcerative colitis, but there are treatments available that directly address the causes of the symptoms and can help achieve and maintain remission.

"The symptoms of Crohn's disease and ulcerative colitis can not only pose physical challenges but also emotional and social ones that can really interfere with everyday life," said Eva Szigethy, Ph.D., M.D., M.S., an associate professor of Psychiatry, Medicine and Pediatrics at the University of Pittsburgh School of Medicine. "There are tips on CrohnsandColitis.com, such as how to build confidence, manage social situations, tackle stress and find motivation, that individuals and their loved ones can put in place. Along with an individualized treatment plan, these tips and tools may help them gain control and better manage the challenges of IBD."

In addition to information on how to build their own IBD Game Plan with their healthcare provider, CrohnsandColitis.com also features tools and information to help manage the physical, emotional and social challenges of IBD. It also features a Restroom Request Card that people living with IBD can use to discreetly request access to restricted restrooms when unexpected symptoms arise.

Please visit <https://www.crohnsandcolitis.com/> for more information.

3 COMMON DIGESTIVE DISORDERS

Celiac Disease

THE BASICS

What it is

Celiac disease is an autoimmune disorder where the ingestion of gluten leads to damage in the small intestine.

COMMON SYMPTOMS

- Abdominal Pain
- Diarrhea and/or Constipation
- Weight Loss
- Nausea
- Fatigue

Causes

Those suffering from the disease cannot tolerate gluten, a protein found in wheat, rye, barley, and some oats. When people with celiac disease consume gluten, their immune systems attack the small intestine and damage the inner lining which is used to absorb nutrients from food.

Affects approximately 2 million people in the U.S.

Treatment

Celiac disease is chronic and there is no known cure. People living with celiac disease must consume a gluten-free diet in order to eliminate symptoms. Gluten is sometimes hidden in processed foods so those with celiac disease are advised to always check nutrition labels and ingredients. However, a person should not begin a gluten-free diet without being diagnosed.

Crohn's Disease

THE BASICS

What it is

Crohn's disease is a severe, chronic inflammatory bowel disease. It causes inflammation, ulcers, and bleeding in the digestive tract.

COMMON SYMPTOMS

- Diarrhea
- Abdominal Cramps and Pain
- Anemia and Rectal Bleeding
- Weight Loss
- Fatigue
- Nausea

Causes

The cause of Crohn's disease is not known, but, like other inflammatory bowel diseases, it seems to run in some families. Some research links Crohn's disease to an overactive and inappropriate immune response to the bacteria that normally reside in the intestine, causing damage to the intestines.

There are about 700,000 people currently living with Crohn's Disease.

Treatment

Your doctor may recommend that you avoid foods that provoke symptoms, which may include:

- Dairy foods (due to lactose intolerance)
- Highly seasoned foods
- High-fiber foods
- Other biologic treatments

Medication or surgery may also be an option.

Other Common Symptoms:

- Fever
- Mouth sores
- Sores, abscesses in the anal area

Irritable Bowel Syndrome

THE BASICS

What it is

Irritable bowel syndrome (IBS) is a disorder that leads to abdominal pain and bowel changes. It is the most common intestinal problem that causes patients to be referred to a bowel specialist (gastroenterologist).

COMMON SYMPTOMS

- Abdominal Pain
- Gas
- Fullness
- Bloating

Causes

The reasons why IBS develops are not clear, but it can occur after an infection of the intestines. Another trigger may be stress. Signals go back and forth between the bowel and brain, which affect bowel function and symptoms. The nerves can become more active during stress, which can cause the intestines to be more sensitive and contract more.

Twice as common in women, affects 1 in 6.

Treatment

Lifestyle changes can help in some cases of IBS. For example, regular exercise and improved sleep habits may reduce anxiety and help relieve bowel symptoms.

The following dietary changes may help:

- Avoiding foods and drinks that stimulate the intestines (such as caffeine, tea, or cola)
- Eating smaller meals
- Increasing fiber in the diet (this may improve constipation, but make bloating worse)

Talk with your doctor before taking over-the-counter medications.

UPMC LIFE CHANGING MEDICINE

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