The "Embarrassing Disease" of the Digestive System

By Cheryl L. Reed
You probably won’t hear inflammatory bowel disease—or IBD, as it’s frequently called—talked about in social settings, and you’re not likely to read of celebrities discussing their treatments in magazines, as they often do with cancer. Jerry Lewis isn’t calling. There’s no IBD telethon.

“It’s an embarrassing disease. We usually do not discuss our bowel functions with family or friends,” said Stephen Hanauer, MD, chief of Gastroenterology, Hepatology and Nutrition at the University of Chicago Medical Center, which has one of the preeminent IBD centers in the world.

IBD is a disease of the digestive tract, extending from the mouth, esophagus and stomach to that series of sausage-like organs below the stomach that extends to the rectum. The disease—actually, a family of diseases that primarily consists of Crohn’s disease and ulcerative colitis—is the result of an abnormal immune response in the digestive tract that results in ulcers, erosions and obstructions in the bowel. The most common symptoms are abdominal cramps, loss of appetite, fever, nausea, vomiting, rectal bleeding and diarrhea. Severe cases can cause massive weight loss or anemia and may lead to bone loss and colon cancer.

Doctors don’t know exactly what causes IBD, but they believe something in the environment triggers a reaction in the body, which results in the inflammation of the digestive system. Somehow the body can’t turn off its fight response, and so the body continually attacks its own organs. Inflammation of the skin, eyes, joints and liver occasionally accompanies the disease. There appears to be a genetic predisposition and about 10 to 30 percent of patients have someone in their family who also has IBD, though the majority who develop this chronic condition have no family history.

In the past, IBD was considered a disease of affluence and most commonly affected middle- and upper-class people, those who lived in northern climates, city dwellers or residents of wealthy suburbs. Caucasians, especially Ashkenazi Jews, were most susceptible. However, IBD is now seen in virtually all ethnic groups and ages as populations assimilate Western diets and lifestyles. Symptoms most frequently appear in patients between the ages of 15 and 35. The average age of diagnosis is 22.

About 1.4 million Americans have been diagnosed with IBD — nearly the same rate as lupus — and the disease is on the rise. Doctors at the Medical Center believe that as many as 2 million people have the disease, but, because they may have a milder form, haven’t sought treatment or are misdiagnosed as the more common irritable bowel syndrome. IBD is most prevalent in North America and Europe but rare in developing nations. It is less common in Southern climates in the U.S. and Europe, areas that are more rural and agricultural. Theories abound about what causes the disease, from super-cleanliness to infections to genetics to bacteria in our guts.

Crohn’s disease can attack any organ between the mouth and the anus, while ulcerative colitis is limited to the large intestine, also known as the colon and rectum. The biggest difference between the two diseases is that Crohn’s disease is a deep tissue inflammation while ulcerative colitis attacks only the superficial lining of the bowel.

“Ulcerative colitis almost looks like you skinned your knee or if you took sandpaper to the bowel and rubbed it and got red,” explained David Rubin, MD ’94, co-director of the Medical Center’s IBD center. “So if you do need surgery, and we remove the entire large intestine, you are cured from the condition.”

Ulcerative colitis usually involves the rectum (called proctitis) but can affect other parts of the colon. Patients often have bloody bowel movements and diarrhea and live in fear of not getting to the bathroom in time.

Crohn’s disease patients can have various symptoms depending on what part of the gastrointestinal tract it attacks. Most commonly, it occurs in the last part of the small intestine and the first part of the colon, often mimicking the pain someone might have with appendicitis. Sometimes, if the disease is only detected in the colon, doctors may have a hard time differentiating between Crohn’s and ulcerative colitis.

Crohn’s disease in the small intestine often causes the patient to have a hard time absorbing nutrients, causing weight loss, anemia and bone loss. The patient may have an obstruction that results in cramping, nausea and vomiting. Patients can get what’s called a fistula, or tract, that connects one part of the bowel to another or to surrounding organs or the areas near the anus, and there can be a lot of draining and pain. In children, the only sign of the disease may be when the child can’t gain weight or doesn’t go through puberty.

Treatment for Crohn’s may involve a variety of medications; many patients require surgical resection of the inflamed parts of the intestines and sewing back together the healthy parts. Crohn’s disease often recurs after surgery, so doctors advise continued medical treatments.

“We cut out the part that is inflamed, but the disease comes back and it comes back right where we sewed things together. So it’s very predictable,” Rubin said.

From left: Some team members that treat IBD include: Roger Hurst, MD, associate professor of surgery; David Rubin, MD, co-director of the Inflammatory Bowel Disease Center; Stephen Hanauer, MD, chief of Gastroenterology and Nutrition; Russell Cohen, MD, co-director of the Inflammatory Bowel Disease Center. Photo by Dan Bry
About one in five ulcerative colitis patients will need to have his colon removed because of how severe the condition is or because of pre-cancerous signs. That procedure previously required patients to have an ileostomy—where the end of the small intestine is attached to an opening in the abdominal wall, allowing waste to drain outside the body into a pouch. Now, specialized surgeons at the Medical Center’s IBD center can reconstruct a functional rectum from the small intestine so that most patients can eliminate normally.

Treatment for Crohn’s or ulcerative colitis usually involves medicines that keep the disease quiet. Most IBD patients have mild or moderately active disease, meaning that they periodically suffer flare-ups interspersed with times when their disease is quiet. About 20 percent of IBD patients have severe cases.

Getting the correct diagnosis is one of the biggest problems for people with IBD. It is not uncommon for patients to suffer for years before doctors are able to identify the disease. The symptoms mirror those of more common ailments, such as hemorrhoids, lactose intolerance or irritable bowel syndrome.

Symptoms of irritable bowel, formerly called spastic colon, are similar to IBD in that patients report abdominal pain, diarrhea and an urgency to go to the bathroom. The difference is that with irritable bowel there are no ulcers or bleeding and no intestinal narrowings or obstructions.

Sometimes IBD can remain dormant in a person’s body until a stressful event triggers an outbreak.

“It’s very common to have had a major life stressor right before the attack,” explained Russell Cohen, MD, the other co-director of the Medical Center’s IBD center. “Often it’s a divorce, death in a family members or loss of a job. They’ve been healthy all their lives and then, bam! Something happens and they have a major event and they have an attack.”

There are a number of tests used to diagnose IBD, ranging from stool and blood samples to MRIs and X-rays. The diagnosis must be confirmed by a colonoscopy, in which biopsies are taken.

IBD, like other immune-related diseases such as multiple sclerosis, asthma, lupus and rheumatoid arthritis, is on the rise and has spurred a number of medical studies to find the causes. The more interesting breakthroughs have been in identifying several genes associated with IBD. Doctors have known for years that there is some genetic component. There’s a greater risk for someone whose parents or siblings have the disease.

“The problem is that we still don’t know what most of the genes do,” said Rubin. “And none of them are predictive in the sense of, ‘Let’s test you for the gene and then we’ll know if you’re going to get the disease or what’s going to happen to you.’”

Less than 15 percent of the IBD patients have one of the known genes for IBD. (The first IBD gene, NOD2, was discovered by researchers at the Medical Center and reported in 2001.) Doctors believe there are probably a number of other genes that actually protect people from getting IBD, but those have yet to be identified.

**IBD Discoveries and Firsts at the University of Chicago**

The University of Chicago was the first institution to establish a full-time department of gastroenterology in 1927.

Longtime professor Joseph Kirchner, MD, PhD ’42, established the first gastrointestinal research lab at the University of Chicago shortly after he was hired in 1935.

Since 1983, researchers at the University of Chicago have been leading clinical trials for new medications.

In 2001, researchers at the University of Chicago discovered a genetic mutation, called NOD2, that is linked to Crohn’s disease.

Now, the Medical Center treats more than 5,000 IBD patients a year. An interdisciplinary clinical team, including gastroenterologists and surgeons that specialize in colorectal cases, treats patients, while researchers study what causes IBD. Clinical trials are merging research and patient care, with a current study investigating a pill to ease the inflammation of ulcerative colitis.
Since Burrill Crohn and his colleagues first described the disease in 1932, doctors have had a number of theories about what causes it.

Among the more fascinating studies are those that suggest exposure to bacteria and parasites in the environment are necessary for the development of a healthy immune system. Children who grow up in rural areas are less likely to develop IBD, allergies and other autoimmune diseases. Scientists are studying this theory by testing exposure to a parasite, the eggs of pig whipworms, as a treatment for IBD.

"These are diseases of cleanliness and hygiene," explained Hanauer. "What's happened over the past 50 years, in the countries where IBD and other autoimmune disease have become more prevalent, is that we've cleaned up the environment. We don't have pinworms any more. We've chlorinated the water. Our environment is sterile compared to the environment of Africa or Asia."

The human body is made up of trillions of bacteria, most of which live in our colon.

"There are more bacteria in our guts than there are cells in our bodies, by 10 times," Hanauer said. "So we are 10 times more bacterial than human. When we evolved, we evolved from bacteria. We learned to live with bacteria."

America's fascination with using antibiotics and antibacterial soaps and even health crazes that promote colonics are actually doing more damage than good, he said. "Our colon is a sewer. It is meant to be a sewer. It is not meant to be sterile. And when you sterilize things, you allow bad stuff to grow."

Cohen believes the disease is largely genetic, particularly Crohn's disease, but is triggered by something in the environment.

"I feel pretty confident in saying that we're never going to say it's one single thing that causes it," he said. "There's so much evidence that suggests it's a variety of things."

Warning Signs:

- Blood in the toilet
- Persistent diarrhea
- Waking up in the middle of the night after a bowel movement
- Unexplained weight loss
- Unexplained anemia
- Not making it to the toilet in time

Preventive Measures:

- Do not smoke cigarettes.
- Avoid exposure to secondhand smoke, particularly if there's a family history of IBD.
- Avoid excess use of aspirin or ibuprofen; use acetaminophen instead.
- Avoid antibiotics unless absolutely necessary.
- Breastfeed children.

Differences between Crohn’s Disease and Ulcerative Colitis:

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<th>Crohn’s Disease...</th>
<th>Ulcerative Colitis...</th>
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<tr>
<td>can attack anywhere in the GI tract, from the mouth to the anus.</td>
<td>is limited to the colon.</td>
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<tr>
<td>is a deep tissue inflammation that moves through the entire wall of the organs it attacks.</td>
<td>attacks the superficial lining of the colon.</td>
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<tr>
<td>is associated with smoking and the most severe cases are in those who are smokers.</td>
<td>is prevented by not smoking.</td>
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<tr>
<td>is associated with abdominal pain.</td>
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<td>often returns to the same areas that were resected.</td>
<td>is cured once the large intestine is removed.</td>
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