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Details:

(FORM UPDATED: 08/11/2010)

WISCONSIN STATE LEGISLATURE ...
PUBLIC HEARING - COMMITTEE RECORDS

2009-10

(session year)

Senate

(Assembly, Senate or Joint)

Committee on ... Small Business, Emergency Preparedness, Technical Colleges, and Consumer Protection (SC-SBEPTCCP)

COMMITTEE NOTICES ...

- Committee Reports ... **CR**
- Executive Sessions ... **ES**
- Public Hearings ... **PH**

INFORMATION COLLECTED BY COMMITTEE FOR AND AGAINST PROPOSAL

- Appointments ... **Appt** (w/Record of Comm. Proceedings)
- Clearinghouse Rules ... **CRule** (w/Record of Comm. Proceedings)
- Hearing Records ... bills and resolutions (w/Record of Comm. Proceedings)
  (**ab** = Assembly Bill) (**ar** = Assembly Resolution) (**ajr** = Assembly Joint Resolution)
  (**sb** = Senate Bill) (**sr** = Senate Resolution) (**sjr** = Senate Joint Resolution)
- Miscellaneous ... **Misc**

* Contents organized for archiving by: Gigi Godwin (LRB) (July/2011)

Senate

Record of Committee Proceedings

Committee on Small Business, Emergency Preparedness, Technical Colleges, and Consumer Protection

Assembly Bill 709

Relating to: requiring access to toilet facilities in a retail establishment, immunity from civil liability related to use of the toilet facilities, and providing penalties.

By Representatives Van Roy, Soletski, Townsend, Berceau, Montgomery, Spanbauer, Knodl, Vos, A. Ott, Brooks, Turner, Pasch, Zigmunt, Roys, Jorgensen, Smith and A. Williams; cosponsored by Senators Lehman, Hansen, Taylor, Coggs and Plale.

March 08, 2010 Referred to Committee on Small Business, Emergency Preparedness, Technical Colleges, and Consumer Protection.

March 16, 2010 **PUBLIC HEARING HELD**

Present: (4) Senators Wirch, Plale, Hopper and Lazich.
Absent: (1) Senator Holperin.

Appearances For

- John Lehman — Senator, 21st Senate District
- Karl Van Roy — Representative
- Daniel Young — State Rep. Soletski's office
- Sydney Allen, Green Bay
- Nadine Davis, Hubertus

Appearances Against

- None.

Appearances for Information Only

- None.

Registrations For

- None.

Registrations Against

- None.

Registrations for Information Only

- None.

March 31, 2010 **EXECUTIVE SESSION HELD**

Present: (5) Senators Wirch, Plale, Holperin, Hopper and Lazich.
Absent: (0) None.

Moved by Senator Plale, seconded by Senator Holperin that **Assembly Bill 709** be recommended for concurrence.

Ayes: (5) Senators Wirch, Plale, Holperin, Hopper and Lazich.
Noes: (0) None.

CONCURRENCE RECOMMENDED, Ayes 5, Noes 0

Michael Tierney
Committee Clerk

Wisconsin State Senate
John Lehman
Senator – 21st District

State Capitol • PO Box 7882 • Madison, WI 53707-7882 • (608) 266-1832 • Toll-free: 1-866-615-7510

Testimony of State Sen. John Lehman
Senate Committee on Small Business, Emergency Preparedness, Technical Colleges, and Consumer Protection
Assembly Bill 709
March 16, 2010

Chairman Wirch, members of the committee, I thank you for holding a hearing on Assembly Bill 709.

I joined with Representatives Karl Van Roy and Jim Soletski in introducing this legislation because of the peace of mind it can provide to those who suffer from inflammatory bowel disease (or IBD), Crohn's or ulcerative colitis. These conditions can often make leaving the house for something as simple as a shopping trip downtown or to a mall a stressful situation.

An estimated 20,000 people in Wisconsin suffer from IBS. The pain experienced by many during a flare up of IBS or related disorders can be unbearable, and sufferers are experiencing symptoms may need to access a restroom immediately.

Many who suffer from these ailments have turned to online shopping as a solution to this problem. By allowing these individuals to use employees-only restrooms in retail establishments, we allow those afflicted with these disorders the freedom to leave the house and allow them to patronize local small businesses.

A similar or identical law has been successfully passed in 9 other states including Michigan, Illinois and Minnesota. AB 709 has the support of the Crohn's and Colitis Foundation of America and the Foundation for Clinical Research in Inflammatory Bowel Disease. Again, I think the committee for their consideration of AB 709. I am available to answer any questions members may have.

Fax: (608) 267-6793 • E-Mail: sen.lehman@legis.wisconsin.gov • Home: 708 Orchard Street • Racine, WI 53405 • (262) 632-3330


FORWARD
E PLURIBUS UNUM

Date: March 16th, 2010

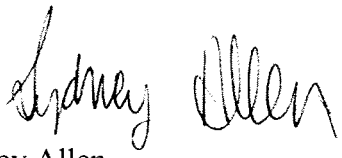
To: Chairman Wirch and Senate Committee on Small Business, Emergency Preparedness, Technical Colleges, and Consumer Protection

Regarding: Assembly Bill 709

Position: Support

Thank you Chairman Wirch, Representative Van Roy, Representative Soletski, and Members of the Committee for having me here today in order to discuss the importance of Assembly Bill 709. I have been living with Crohn's Disease for four years now, and I was diagnosed during my junior year of high school in 2006 after enduring nearly a year of ongoing, agonizing, and unidentifiable pain. It was another year of ups and downs, however, before I finally had my disease under control. At the time of my diagnosis I weighed only ninety pounds, and suffered from excruciating bouts of stomach pain, diarrhea, excess gas, and fatigue. Once properly diagnosed I learned all I could about the specifics of my disease, including the fact that it was a chronic and often embarrassing illness that I would have to learn to live with throughout the rest of my life. When afflicted with Crohn's Disease, one must learn to live with the unexpected. It is a terrifying thing, not having control over your own bodily functions, and not knowing when or where an urgent trip to the bathroom may be required. It is especially unsettling in unfamiliar public places, where the locations of the nearest restroom may be unknown or unmarked. While most girls my age scour public arenas for the best restaurants or the greatest shopping bargains, I am always in search of the nearest restroom, never knowing when an urgent need for one will arise.

Unfortunately, living with Crohn's Disease does not allow sufferers the luxury of time. In fact, time becomes a limited window of opportunity. If there is not an accessible public restroom near enough to an individual in order to immediately accommodate them, there may very well be an accident. Assembly Bill 709 is essential in maintaining the physical and mental health of individuals with Inflammatory Bowel Diseases. Living with an incurable disease of unknown etiology is difficult for all, and the passage of this legislation into law will make a world of a difference to those suffering with IBD. With a disease that keeps the afflicted living in the unknown, the comfort and security that this law will provide will be monumental in the assurance of worry-free public environments for all IBD patients. I encourage you to vote in favor of passing Assembly Bill 709 into law, for it will undoubtedly ease the minds of countless Wisconsinites who are currently hesitant in venturing to many a public place. Thank you.



Sydney Allen
920-737-5393
Sydney.allen@marquette.edu


FORWARD
E PLURIBUS UNUM

AB 709 (Date?)

Sen. Lehman w/
Attached -


FORWARD
E PLURIBUS UNUM

Date?

KARL VAN ROY

STATE REPRESENTATIVE

Testimony in support of Assembly Bill 709 – Restroom Access Act

Thank you Chairman Wirch and members of the committee for taking the time to hold a public hearing on this important legislation. I appreciate you scheduling the bill so promptly given the lateness of the legislative session. I'm pleased to report that this bill has already passed an Assembly Committee on a unanimous vote and it passed the Assembly floor on a voice vote. No individual or group has registered or testified in opposition to this legislation.

Inflammatory Bowel Disease (IBD), which includes Crohn's disease and ulcerative colitis, is a chronic disorder that causes inflammation in the gastrointestinal tract. IBD symptoms come on suddenly and urgently and include severe abdominal pain and diarrhea. Individuals experiencing symptoms need access to the most conveniently located bathrooms without delay.

A constituent of mine who has Crohn's disease brought to my attention the story of teenager Ally Bain, a fellow Crohn's sufferer in Illinois. At the age of 14, Ally was shopping at a national retail clothing store with her mother when her Crohn's disease suddenly flared up and she had to use the restroom immediately. They asked an employee and then a manager for permission to use the employee-only restroom, but she was refused by both of them because of what they called, "store policy." As a result, Ally suffered a humiliating accident right there in the store. Ally and her mother vowed to make sure that this situation never happened again to her or anyone else suffering from IBD.

Ally and her mother worked with their state legislator to find a solution, and they got "Restroom Access Act" legislation passed in Illinois in 2005, also known as "Ally's Law". Assembly Bill 709 is similar to Ally's law. Under AB 709, retail establishments with at least three employees on duty must provide access to employee-only restrooms to those individuals who have Crohn's disease or ulcerative colitis or use an ostomy device when a public restroom is not readily available. Businesses do not have to make any alterations to their facilities to accommodate these individuals, and they are protected from liability if someone accessing the employee-only restroom would get hurt. Businesses do not have to allow access if it creates an obvious health or safety risk to the person or an obvious security risk to the business. In addition, AB 709 requires the person to show a doctor's note or approved ID card that shows he or she has an eligible medical condition.

In addition to Illinois, similar Restroom Access laws already exist in Minnesota, Michigan, Texas, Tennessee, Colorado, Kentucky, Washington, and Connecticut. Bills also have been proposed in Delaware, Florida, Massachusetts, Ohio, New York, New Jersey, Georgia, Missouri, Virginia, New Mexico, Oklahoma, Wyoming, South Carolina, Rhode Island, Indiana, and Pennsylvania.

Capitol Office: Post Office Box 8953 • Madison, WI 53708-8953
(608) 266-0616 • Toll-Free: (888) 534-0090 • Fax: (608) 282-3690 • Rep.VanRoy@legis.state.wi.us
Residence: 805 Riverview Drive • Green Bay, WI 54303 • Phone: (920) 662-0804

Van Roy Testimony in support of Assembly Bill 709 Restroom Access Act (cont'd)

According to the Crohn's and Colitis Foundation of America, 1.4 million people nationwide suffer from Crohn's disease or ulcerative colitis, of which it is estimated 20,000 live in Wisconsin. At least 10% of sufferers are under the age of 18. Alarmingly, studies show that Wisconsin has the highest incidence rate of pediatric Crohn's Disease in the world. AB 709 is a good, bi-partisan bill that will help constituents in all of our districts.

My late sister had Crohn's disease, and it took me a while before I fully realized what a person with Crohn's has to go through on a daily basis. They suffer in silence because it is a very private and personal ailment. For those who suffer from these disorders, this is not a trivial or laughing matter. Going out in public is an extremely scary thought when you don't know if you will have access to a toilet when you need it. The fear of having a humiliating accident in public makes IBD sufferers shy away from going out in public and they often become reclusive in their own homes.

AB 709 restores the confidence and the freedom for people to go out in public once again due to the fact that a toilet facility will be available when they need it. The Restroom Access Act is an important quality of life bill that will make a positive difference in the lives of many without being a burden on businesses. In fact, local businesses will benefit because these individuals will now venture outside and shop in hometown stores rather than buy from out-of-state stores over the internet.

Known Supporters of the bill include:
Ally Bain, the originator of "Ally's Law", and her mother Lisa Bain
Wisconsin Chapter of the Crohn's & Colitis Foundation of America
International Foundation for Functional Gastrointestinal Disorders
Foundation for Clinical Research in IBD
United Ostomy Associations of America, Inc.
Green Bay Area Ostomy Support Group
Beloit Area Ostomy Support Group
Jefferson County Ostomy Support Group
Fox Valley Ostomy Support Group
Chippewa Valley Ostomy Association
Waukesha Ostomy Support Group
Tri-State Wisconsin Ostomy Support Group

Thank you for your time, and I would urge the committee to hold an executive session soon to pass AB 709.

Now, I will turn it over to Dan Young, Research Assistant to Rep. Jim Soletski who has co-sponsored this bill with me.

Members of the Senate Committee on Small Business, Emergency Preparedness, Technical Colleges, and Consumer Protection:

My name is Samantha Toigo and I am a 22-year-old recent Marquette graduate originally from Green Bay. I'm now working as an accountant in Milwaukee. I would like to thank you for bringing AB 709, the Restroom Access Act, to a public hearing. As a Crohn's disease patient, this bill means a lot to me and all the other thousands of Wisconsin residents with inflammatory bowel disease (IBD). I have corresponded with Representatives Van Roy and Soletski several times over the past few months to lend my support to this bill and I am thrilled that it is finally before the public.

I was diagnosed with Crohn's disease last March after suffering the symptoms for about two years without knowing the cause. For those two years I dealt with excruciating abdominal pain and hours of diarrhea whenever I drank caffeine or ate fruits, vegetables, or spicy food, among other causes. I'll spare you the medical details. What disappointed me even more was that I missed out on several once-in-a-lifetime events, not to mention hours of valuable study time, during my last year of college because I was having flares and couldn't leave my apartment.

No matter how well controlled our cases are, IBD patients like me live in constant fear of a sudden flare-up, whether it's due to stress, hormones, something we eat or drink, or even no trigger at all. Even a mild Crohn's or colitis episode can put a patient out of commission for an entire day or night, and in more severe cases patients may spend weeks or even months in the hospital recovering from a flare or surgery.

Crohn's, colitis, and ostomy patients want to live their lives as normally as possible. When our disease flares up when we're in public, patients need to have easy, quick access to a restroom, or we could encounter a situation a *thousand* times more embarrassing than a college student explaining to her friends that she's missing out on an important commitment because of her bowels. Opening employee restrooms to patients with these qualifying conditions when they are in need will help to increase their quality of life and ease their anxiety about going to new or unfamiliar places of business.

That is why I urge you to join me in supporting the Restroom Access Act. AB 709 will enhance the quality of life for gastrointestinal patients by asking retail establishments to extend them a simple act of kindness when they are in need.

I am aware that small business owners have concerns over the impact this bill would have on them, whether it is safety-related or concerns about over-regulation. I feel that the conditions that would be required for this act to be enforced, including the requirement of having at least three employees working, there being no safety hazard in getting to the restroom, and exemption from liability for injuries of the customer are sufficient to preclude any major impact on business as usual for employers.

I would also hope that most employees in Wisconsin would be kind enough to grant someone with these medical conditions access to the restroom. I share the same fear of over-regulation as the small business owners do, but I simply see this law as protection for the patients who might encounter the rare situations where that simple kindness is not

shown. As awful as it is, this has been the case in several situations in the USA, including the case of Ally Bain in Illinois, as well as several cases in the UK.

Thanks in large part to Ally, a teenage IBD patient who started the national push for acts similar to this one, bills like AB 709 have already been passed or are pending in a majority of states, and it's time for Wisconsin to join them. The Milwaukee area alone has the highest number of pediatric IBD patients in the country, and if not for Crohn's and colitis patients in general, I ask you to strongly consider this bill for those children who will live with these diseases for their entire lives or until we find a cure.

To the members of the Committee and the State Senate, please know that by making this bill law, you will truly make a huge difference in the lives of thousands of Crohn's, colitis and ostomy patients across the state. Thank you for your time, and thank you to Representatives Van Roy and Soletski and Senator Lehman as well as all of the others who have worked so hard to make the Restroom Access Act a reality.

Sincerely,

Samantha M. Toigo

Kenneth Kwaterski
836 E. Foxmoor Lane
Appleton, WI 54911

Members of the Senate Committee on Small Business, Emergency Preparedness, Technical Colleges, and Consumer Protection,

My name is Kenneth Kwaterski, I am 19 years old and a Wisconsin native. At the age of 17 I was diagnosed with colitis, a form of Inflammatory Bowel Disease similar to Crohn's, the only difference is the location of the disease. Intestinal disorders are a big part of my life as both of my older sisters have been diagnosed with IBD. It has been a challenge for all three of us in our treatments of the disease, however we do not let it affect out day-to-day lives.

I first found out about the Restroom Access Act (AB 709) a year ago, at the time I knew it as "Ally's Law" named for the girl who at 15 began work to start this very bill. Shortly after I got in contact with her, Ally Bain, and asked what I could do to get this passed in Wisconsin. I am glad Rep. Van Roy has reintroduced it into legislature.

In response to much criticism this Act has faced, I simply ask those who are opposed: how will this really affect your daily actions? This Act is only meant to provide piece of mind for all patients with these kinds of disorders so they can go out patronizing their favorite businesses. How can business owners oppose this Act, when the goal is to keep the customers happy and coming back? I for one would not return to a business if I were treated poorly for whatever reason, not just being denied a restroom. I am stunned to hear some critics' claim this would open up the door for possible thefts, etc. However, I assure you when an IBD patient like myself is experiencing symptoms the only thing on our mind is avoiding accident and finding a restroom. You're morals must be completely out of whack if you impersonate someone with Crohn's just to gain access to the backrooms of businesses in order to "case the joint." I know this is a very strong opinion but I can guarantee if you know someone or have this disease you are appalled to hear people would think this way. Crohn's and colitis are very misunderstood diseases, but are diseases nonetheless and affect people just as must as diabetes. Another task I hope this Act accomplishes is increasing awareness for such disease so that in the future laws like this aren't even needed because people understand the situation. It's incredible we even need a law to say you can use the bathroom; I'm sorry I know you are in pain and crumpled on the floor, but our bathroom is for employees only. It's easy to hope that those who turn people's request for a bathroom down one day find themselves in a similar situation, but that wouldn't solve the problem; and as Ghandi said "An eye for an eye makes the whole world blind." So let us be grown ups here and get past our petty concerns and let people take care of one simple need. To put in perspective, it is difficult enough living with a disease that can be embarrassing, but denying us a restroom when desperately needed is the same as refusing insulin to a diabetic.

Thank you for you consideration on the Restroom Access Act

Kenneth Kwaterski

Kenneth Kwaterski
Ken.kwaterski@gmail.com 3/10/10

Became law in 2009

KOMO News - Seattle, Washington

Print this article

Pearl Jam star lobbies for restroom access

by BRIAN SLODYSKO Associated Press Writer

Originally printed at http://www.komonews.com/news/38668717.html

OLYMPIA, Wash. (AP) - As the lead guitarist for Seattle rock band Pearl Jam, Mike McCready has toured the world, won a Grammy and performed with the Rolling Stones.

But as McCready knows, there are some things fame can't get you. And sometimes, that means getting to a restroom in time.

McCready suffers from Crohn's disease, a painful gastrointestinal disorder that can make finding restrooms an extremely urgent and embarrassing task. On Thursday, he asked Washington state lawmakers to mandate emergency access to businesses' private restrooms for sufferers of Crohn's and related disorders.

"Imagine the worst diarrhea you've ever had, and then times it by 10, with a knife in it," McCready said after testifying before a legislative committee. "You have maybe a half-a-second to find out where a bathroom is."

The proposal would require retailers without public restrooms to allow people with inflammatory bowel diseases to use employee restrooms, provided an identification card or a letter from a doctor or nurse is shown.

There would be some exceptions for small businesses, but if the bill becomes law, those who refuse to open up their restrooms to qualified people could eventually be fined $100.

Illinois, Michigan and Texas have passed similar laws, according to the National Conference of State Legislatures.

The bill's sponsor, Rep. Marko Liias, D-Mukilteo, said the idea came from a constituent with Crohn's disease. Statistics show nearly 30,000 people in Washington are affected by inflammatory bowel disease, Liias said.

"In general, as a society, we are loath to talk about the restroom and going to the restroom," Liias said. "For many people, the simple act of going to the restroom can be an excruciating experience."

McCready said his Crohn's attacks often happen at the most inopportune moments.

"I was in the middle of a solo and it hit, and I can't go anywhere because I'm playing in front of 20,000 people," McCready told The Associated Press after he testified. "So I just let go. I went back stage and cleaned up, because the show must go on."

Another attack happened just before McCready took the stage during a Pearl Jam-Rolling Stones concert, leaving him rushing for a portable toilet.

Pearl Jam made its name in the early 1990s, part of an explosion of grunge rock acts that helped put Seattle on the map.

The band also is known for publicly fighting ticket-sales giant Ticketmaster, but McCready said he was still nervous testifying at the state House Judiciary Committee.

Officials from bank and restaurant associations raised some concerns about the proposed law.

Washington Restaurant Association lobbyist Michael Transue said allowing members of the public with inflammatory bowel diseases to use employee restrooms could create safety issues, particularly if they had to travel through busy kitchens during peak business hours.

"We're very sympathetic to the issue presented," Transue said. "To allow folks in these situations to use our employee restrooms is the humane and compassionate thing to do ... that said, imposing mandatory requirements" is not fair to businesses.

McCready said a law is needed because many businesses are insensitive to the needs of people who have diseases like Crohn's. He said there are a number of businesses he won't patronize because they've denied him emergency restroom access.

Over the past 20 years he estimates that he's had "hundreds" of accidents. But while Crohn's disease has been a public embarrassment for him, he said officials should remember the everyday people who suffer with similar disorders.

"I'm 42 years old. I'm doing fine," he said. "But when you're 13 or 14 and you're going through those years with the shame and indignation - it's embarrassing."

Opening Doors

The story of Ally's Law - Legislating access to restrooms

By Joanne Olshan

Ally Bain could not have predicted the enormous effect she would have on peoples' lives, particularly those living with inflammatory bowel disease, an ostomy or related conditions. Something profound happened to this young girl from the suburbs of Chicago when she was only 14. It was a humiliating incident, not something you'd readily share with others and certainly not with strangers. But that's exactly what Ally Bain did.

In 2001, Ally was plagued with stomach aches and fevers that proved to be much more serious than a lingering case of the flu or lactose intolerance. She was diagnosed with Crohn's disease (CD) at only eleven years old. While there is no cure for this autoimmune disorder involving the gastrointestinal tract, some cases can be managed with medication. It may even go into remission with no symptoms at all, but it is a chronic condition that can flare up at any time. Some cases can be severe enough to require an ostomy. Living with CD can be a lot to deal with for an adult, let alone a child.

Ally was determined to live life as normally as possible, so she persevered at school, took a regimen of medication and developed a high tolerance for pain. She entered high school in 2004 as the fevers and stomach aches persisted and trips to the restroom became increasingly more frequent, sometimes up to 40 times per day. When curious classmates asked why she made so many trips to the restroom, she simply told them.

Ally explains, "I wanted to be straightforward with people. I didn't want the disease to mask the rest of my life and by telling people what was going on, I built a stronger support system." Her greatest supporters are her parents who, despite Ally's praise, say there were times when they felt helpless. Her mother kept Ally on a regular routine hoping it would help her daughter cope and remembers that, "Finding the right mixture or the right medication was difficult. She had been on medication for a while without much success."

On one seemingly ordinary day, Ally and her mom went shopping at a popular retail store. Suddenly, Ally began to feel pain and needed to use the restroom. Lisa asked one of the store employees if her daughter could use the washroom, but was told no. As Ally's discomfort intensified, her mother asked to speak with the manager who also denied a growingly uncomfortable Ally access to their bathroom.

Lisa tried desperately to make the manager understand Ally's medical condition and the urgency of having to use the restroom. Her daughter stood by her side with both arms wrapped around her stomach in excruciating pain. The manager was adamant in his refusal, claiming that company policy did not allow him to do otherwise. He suggested that they go across the street where there was a public washroom. That was not a realistic option and consequently, Ally had an accident in the store.

As mother and daughter headed for home, Lisa's anger was palpable. She vowed never to let Ally be humiliated like that ever again. "At that moment I didn't really know what I was going to do about it. I was very, very upset," recalls Lisa.

She called the corporate headquarters of the store and e-mailed the CEO who implemented a new store policy regarding the use of the employee restroom effective the day after he was contacted by Lisa. But it didn't stop there. Ally's father contacted the media. The first reporter to cover the story was Nesita Kwan from the NBC affiliate in Chicago and not long after, every media outlet in Illinois told the story of the 14-year-old girl with CD who was denied access to the restroom.

Ally at a press conference for the University of Chicago Medical Center. She read her poem about her stay in the hospital for Crohn's - she was 16.

And that might have been the end of it had Ally not remembered the field trip that her eighth-grade class took to Springfield, IL, for a tour of the state capitol. Ally met Illinois State Representative Kathleen Ryg of the 59th district who told the eighth-graders to be sure to contact her if they ever needed anything. Ally decided to take Representative Ryg up on her offer.

After Ryg was contacted by Ally and her mom, she did some research and discovered that there were no restroom access laws in Illinois. So, she and Ally wrote the language for a proposed bill, appropriately named Ally's Law. Eventually, it was introduced to a judiciary committee, the majority of whom had a legal background. Ryg based the wording on similar initiatives in other states and had the Crohn's and Colitis Foundation of America review the proposal.

But, Ryg said, "I learned that even good ideas can be a problem." Putting new requirements on retailers meant securing their support, so she reached out to the Retail Merchants Association and the Convenience Store Operators. In some cases, it was argued, the proposed legislation was not feasible for safety reasons and the lack of employees in some convenience store operations. Adjustments would need to be made.

Absent days at school started to accumulate, but she tried hard to keep up with all the work. At one point, the severity of her pain was so bad that during an examination when a doctor gently touched Ally's stomach, she nearly leaped off the table. Her CD caused a perforation of the colon and she needed emergency surgery.

At Advocate Lutheran General Hospital in Park Ridge, IL, part of Ally's diseased intestine was removed and a temporary colostomy was created. This involved bringing one end of the large intestine through the skin for a stoma and temporarily stapling closed the other end. The emergency surgery was a success, but learning how to change her ostomy bag was challenging.

In January of 2005, Ally traveled to Springfield to testify in front of the judiciary committee. When she was called upon to speak, she read a couple of paragraphs that she had written in her hotel room the night before. Ally was very poised as she articulated what had happened to her and why a law was needed.

According to Ally, "When I was done the committee members' faces expressed anger and empathy." Representative Ryg also addressed the committee, as well as the convenience store operators and the merchants that were in attendance. Representative John Fritchey encouraged everyone to get this passed because he has a "dear friend" with Crohn's disease.. There was such over-whelming support, that the bill passed on "unanimous leave" meaning that there was no need to vote.

Representative Ryg then presented the bill to the Illinois House of Representatives, where it also passed unanimously and then to the Illinois Senate where it was again very well received in another undivided vote. Representative Bill Black applauded the effort and encouraged everyone to vote for it. And all along the way, the list of Ally's Law supporters grew, including the petroleum industry and UCB Pharmaceutical Company as well as support from individuals who wrote letters when they heard about Ally's story through the extensive media coverage.

In August of 2005, eight months after legislation was first introduced by Ally and Representative Ryg, the Restroom Access Act, commonly known as Ally's Law, was signed into law by Illinois Governor Rod Blagojevich. The law requires businesses to make employee–only restrooms available to people with CD, inflammatory bowel disease and other eligible medical conditions including those who utilize an ostomy device, are pregnant or have incontinence.

Restrooms have to be located in areas that will not present a risk to the customer or a security risk to the retail establishment which must have three or more employees and does not include gas stations. Proof of a medical condition is not required to access an employee–only restroom as merchants are expected to be aware of the law; however, CCFA offers a card which one can present if necessary.

During the same yearDr. Fichera at the university of chicago medical center children's hospital performed her second surgery to take down the ostomy and reconnected her intestine. This time however, Ally's recovery didn't go as smoothly as the first surgery. One week after being released from the hospital, she was re-admitted because of an infection. With fevers that spiked to 104 degrees and two different strains of bacteria in her blood, Lisa was told that her daughter would either get better or end up in intensive care. Slowly but surely, Ally began to show signs of improvement until she was well enough to go home following a month-long stay in the hospital.

Dr.Rubin took Ally off all previously prescribed medications and started a new treatment regimen. By now a 15-year-old high school sophomore, Ally seemed to thrive. She developed a very close relationship with Dr. Rubin, who she sees every three months for check-ups and to chat about things that are medically unrelated.

Ally had one more surgery in 2006 to remove some scar tissue that was practically closing her intestine. Her CD has been in remission for two years now and she looks to the future without trepidation. Both Lisa and Ally emphasize the importance of having a great doctor/patient relationship.

"Doctors need to be pro-active. They need to be three steps ahead and you need to believe in them. The doctors who tell you to feel free to get a second opinion are the ones you want to see," asserts Lisa.

Ally Bain with her mother Lisa.

Ally continues to inspire others to initiate Ally's Law in the state where they live. The law has passed in IL, TX, MN, KY and CO. It is pending in ten more states. If you're interested in starting a restroom access initiative, you can visit www.crohnsandme.com and click on the "Advocacy Center" link.

You'll find information about sending a letter or e-mail to your state representative to make them aware of Ally's law and get the process going. Ally recommends that you include personal experiences. You can also read the Restroom Access Act law by simply entering it in any search engine..

"As more and more states pass the law, it shows there is a need and puts it on the radar for federal legislators," said Ryg. In an effort to speed up that process, she and Ally are planning a letter writing campaign to all state senators which will include information about Ally's Law, her personal story and a call to action.

Ally is now a freshman in college. She also has an occasional speaking engagement where she talks about living with CD and the undignified circumstance that ultimately resulted in Ally's Law. "Try not to keep your condition secretive," advises Ally. "It helps to be vocal about it. Know that you're not alone. Have a good relationship with your doctor and surround yourself with people who support you. There are answers out there." And perhaps no one knows that better than Ally Bain.

Nancy J. Norton
President and Founder

International Foundation for Functional Gastrointestinal Disorders

March 11, 2010

The Honorable Karl Van Roy and
Members of the Senate Committee on Small Business, Emergency Preparedness, Technical Colleges, and Consumer Protection
123 West
State Capitol
P.O. Box 8953
Madison, WI 53708

Dear Representative Van Roy and Committee Members:

As president of the Wisconsin-based nonprofit organization, the International Foundation for Functional Gastrointestinal Disorders (IFFGD), I am writing to let you know that IFFGD strongly supports legislation Assembly Bill 709, also known as the *Restroom Access Act*, for its provisions requiring businesses to make employee-only restrooms available to people with irritable bowel syndrome (IBS), inflammatory bowel disease, incontinence, and other medical conditions. Furthermore, the IFFGD calls on other members of the Wisconsin State Legislature to show strong character and leadership by supporting Assembly Bill 709 as well.

IFFGD was founded in 1991 to inform, assist and support people affected by functional gastrointestinal and motility disorders, such as IBS. IBS affects more than 30 million men and women, an estimated 10 to 15 percent of the U.S. population. It is a chronic illness characterized by unpredictable pain and bowel symptoms. It is a potentially disabling condition that is invisible to others.

Since founding IFFGD, I, personally, have talked to thousands of patients who must live with the daily challenges of IBS. Many patients manage the symptoms that can flare-up with no warning by staying home more often as a way to accommodate them. They no longer participate fully in daily life.

On a personal level, I can attest to the need to know that a bathroom is available if needed. I founded IFFGD because of my own experiences with digestive disorders. I can say from personal experience that many people do not understand when I tell them I cannot wait to use the bathroom. To know that a bathroom would be available would make a difference to me and to all others who have digestive disorders.

IFFGD, PO Box 170864, Milwaukee, WI 53217
Phone: 414-964-1799 Fax: 414-964-7176 E-Mail: iffgd@iffgd.org

Representative Karl Van Roy and Committee Members ... 2

This bill will help educate store owners about the need to provide bathrooms to people with digestive disorders. It also will help reassure those of us who are affected that we can go out in public knowing a bathroom will be available if necessary.

On behalf of all the people affected by digestive conditions, I thank you for introducing Assembly Bill 709, and I encourage the Wisconsin State Legislature to move this bill forward.

Sincerely,

Nancy J. Norton
President and Founder

CROHN'S & COLITIS
FOUNDATION OF AMERICA
WISCONSIN CHAPTER

February 11, 2010

The Honorable Karl Van Roy
90th Assembly District
123 West, State Capitol
P.O. Box 8953
Madison, WI 53708

Dear Representative Van Roy,

The Crohn's & Colitis Foundation fully supports the Wisconsin Assembly Bill 709 and thank you for helping improve the lives of the over 25,000 Wisconsin residents living with Inflammatory Bowel Disease.

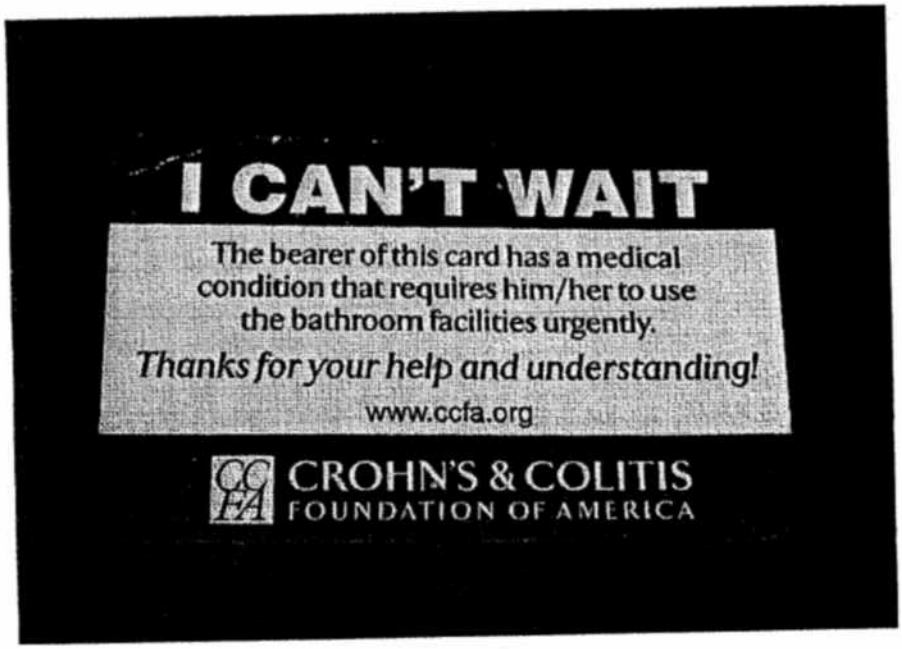
Our Mission at the Crohn's & Colitis Foundation is *To cure Crohn's disease and ulcerative colitis, and to improve the quality of life of children and adults affected by these diseases.* We sincerely appreciate the work you are doing, as it is furthering our mission.

Regards,

Tyler Hillstrom
Executive Director
CCFA – WI Chapter

1126 South 70th Street, Suite S210A West Allis, WI 53214
Telephone: 414-475-5520 Fax: 414-475-5502 Toll Free: 877-586-5588 Email: infowisconsin@ccfa.org
National Headquarters: Tel: 800-932-2423, Email: info@ccfa.org, Internet: www.ccfa.org
A Proud Member of Community Health Charities

Samples of Identification cards:



The card reads:

MEDICAL ALERT
Restroom Access Required
The holder of this card has Crohn's disease
or ulcerative colitis. Colitis is painful and requires
immediate access to a toilet facility.
This patient cannot physically "hold it."
Please make your restroom available.

THE FOUNDATION FOR CLINICAL RESEARCH
IN INFLAMMATORY BOWEL DISEASE

2595 S. Trillium Circle
Green Bay, WI 54313
March 14, 2010

Re: Wisconsin Restroom Access Legislation

To Whom it May Concern...

I understand you are considering passing legislation for access to restrooms in medical emergency situations. I would like to tell you emphatically to **vote YES** for it!

I have had an ileostomy for 22 years and had ulcerative colitis for 8½ years prior to that. Inflammatory bowel disease (IBD - ulcerative colitis and Crohn's disease) is a horrible thing to live with. It usually strikes those in their teens and 20s and can last a lifetime. I had urgent diarrhea (needing a restroom within a minute or two of the "feeling"), 10 - 25 times a day for most of the 8½ years I had it. I stayed home most of the time for fear of an "accident".

Many stores would not let me use their restrooms and would tell me to go to the central restrooms in the mall. They were too far away and would take too long to get to. I often had two tiny children in tow. So I stayed home. What a life to live all of my 30s!

Now that I have my ileostomy, I no longer have colitis. However, on rare occasions, I "spring a leak" where my ostomy appliance loosens and stool gets all over me and my clothing. In these rare situations, it would be wonderful to know that I could immediately get to a restroom to care for myself before the damage got too bad. Right now, that is not always the option because many stores still restrict people like me from using their restroom.

Those of us afflicted with IBD and ostomies would love the freedom of knowing that we would no longer be in embarrassing, devastating situations when medical emergencies arise. We would NOT abuse the privilege! It would allow us to lead a more normal life.

Please vote to enact the Restroom Access legislation!!

Sincerely,

Chris Demeuse
(920) 499-8742

Hein, Tanya

From: Kolar, Debra A. [Debra.Kolar@NWTC.EDU]
Sent: Monday, March 15, 2010 1:39 PM
To: Sen.Wirch
Cc: Rep.Van Roy; Barb Drzewiecki; ndavis@ccfa.org
Subject: Bill 146.29
Importance: High

Dear Senator Wirch;

I hope this isn't too late; I realize there is a public hearing tomorrow at 9:00 a.m. on this Bill.

I cannot express how important this issue is for those of us who suffer from Crohn's or Colitis. I am a 43 year old woman who was diagnosed several years ago with Ulcerative Colitis. I currently take medication every day to keep me "in remission" from flare ups, however I still suffer them. The medication requires blood work every six months for adverse liver reaction. I am currently taking a high dose, six week regimen of prednisone to conquer a flare up. I have eaten one piece of toast today. As Crohn's and Colitis sufferer's we know that everything that goes in, must come out, those of us with these diseases often have no control of "when" that happens..... we just pray we have access to or can make it to a bathroom.

These are painful and humiliating disease's. Many people will not talk openly about them, I however will talk to anyone and everyone if it helps make life with these conditions tolerable. My condition has caused me to avoid going places that do not have access to restrooms.

I returned last week Thursday from a vacation in Cancun. I brought a note from my doctor that I could share with the airline in the event I had to use the restroom on the plane during the time when they tell you "you must remain seated". One flight attendant told me if I had a condition that would cause a "rule" to be broke, I should not be allowed to fly. ARE YOU KIDDING ME???? Because I may need to use a bathroom??? The stress of this alone caused me unnecessary anxiety.

This Bill is a start to helping those of us with these diseases. I appreciate your support.

Thank you for your time.

Debra Kolar
3494 Mardon Lane
Green Bay, WI 54313


FORWARD
E PLURIBUS UNUM

CROHN'S & COLITIS
FOUNDATION OF AMERICA

Living with Ulcerative Colitis

CROHN'S & COLITIS
FOUNDATION OF AMERICA

Our Mission:
To cure and prevent Crohn's disease and ulcerative colitis through research, and to improve the quality of life of children and adults affected by these digestive diseases through education and support.

888.MY.GUT.PAIN
www.ccfa.org

National Office
386 Park Avenue South
17th Floor
New York, NY 10016-8804

The printing of this brochure was made possible by an unrestricted grant from:

P&G Pharmaceuticals

04/07

UNDERSTANDING THE DIAGNOSIS

Your doctor has just told you that you have a disease called ulcerative colitis. Quite possibly, you have never even *heard* of this condition before. (Most people, in fact, are unfamiliar with ulcerative colitis.) And now you have it. And, to make matters worse, your doctor has said that ulcerative colitis doesn't go away.

If you feel overwhelmed and scared right now, that's only natural. You probably have a ton of questions, starting with "Just what *is* ulcerative colitis?" But you're also wondering how you got it and, more important, how it will affect you—both now and down the road. For example, you'll want to know:

- Will I be able to work, travel, exercise?
- Should I be on a special diet?
- Will I need surgery?
- How will ulcerative colitis change my life?

That's the purpose of this brochure: to answer those questions and to walk you through the key points about ulcerative colitis and what you may expect in the future. You won't become an expert overnight, but gradually you'll learn more and more. And the more you know, the better you'll be able to cope with the disease and become an active member of your own health care team.

WHAT IS ULCERATIVE COLITIS?

Ulcerative colitis belongs to a group of conditions known as *inflammatory bowel disease (IBD).* Another illness in this group is Crohn's disease. Both conditions cause diarrhea (sometimes bloody), as well as abdominal pain. Because the symptoms of these two illnesses are so similar, it is sometimes difficult for doctors to make a definitive diagnosis. In fact, approximately 10% of cases are unable to be pinpointed as either ulcerative colitis or Crohn's disease.

While Crohn's disease may affect any part of the gastrointestinal (GI) tract, ulcerative colitis is limited to the colon—also called the large intestine. The inflammation begins at the rectum and extends up the colon in a continuous manner. There are no areas of normal intestine between the areas of diseased intestine. In contrast, such so-called "skip" areas may occur in Crohn's disease. And whereas Crohn's disease can affect the entire thickness of the bowel wall, ulcerative colitis only involves the innermost lining of the colon—causing it to become inflamed. Tiny open sores or ulcers form on the surface of the lining, where they bleed and produce pus and mucus. In short, ulcerative colitis is an inflammatory disease of the lining of the colon.

The more you know, the better you'll be able to cope with the disease.

What does "chronic" mean?

No one knows exactly what causes either ulcerative colitis or Crohn's disease. Also, no one can predict how the disease—once it is diagnosed—will affect a particular person. Some people go for years without having any symptoms, while others have more frequent flare-ups of disease. However, one thing is sure: ulcerative colitis —like Crohn's disease—is a chronic condition.

Chronic conditions are ongoing situations. They can be controlled with treatment but cannot be cured. That means that the disease is long-term, but it does *not* mean that it is fatal. It isn't. Most people who have ulcerative colitis lead full and productive lives.

A BRIEF INTRODUCTION TO THE GI TRACT

Most of us aren't very familiar with the gastrointestinal tract (GI), even though it occupies a lot of "real estate" in our bodies. Here's a quick tour:

The GI tract actually starts at the mouth. It follows a twisting and turning course and ends, many yards later, at the rectum. In between are a number of organs that all play a part in processing food and transporting it through the body.

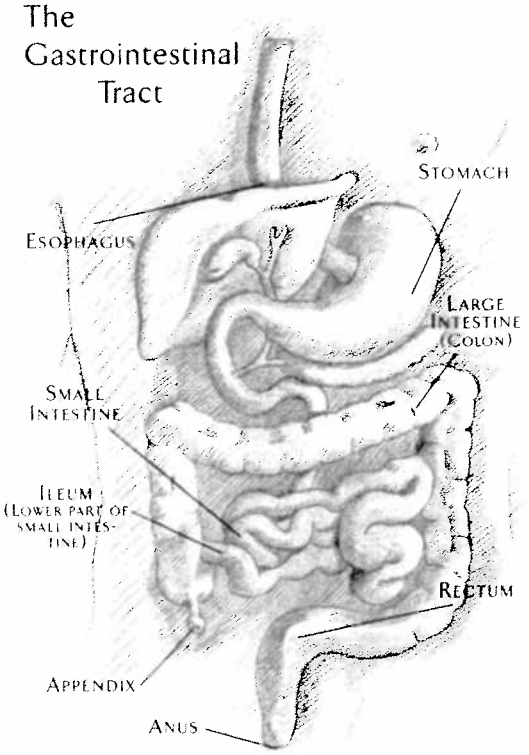
The first is the esophagus, a narrow tube that connects the mouth to the stomach. After that comes the stomach itself. Moving downward, the next organ is the small intestine. That leads to the colon, or large intestine, which connects to the rectum.

The principal function of the colon is to absorb excess water and salts from the waste material (what's left after food has been digested). It also stores the solid waste, converting it to stool, and excretes it through the anus.

The inflammation in ulcerative colitis usually begins in the rectum and lower colon, but it also may involve the entire colon. Ulcerative colitis may be called by other names, depending on where the disease is located in the colon.

- **Ulcerative proctitis:** involves only the rectum
- **Proctosigmoiditis:** affects the rectum and sigmoid colon (the lower segment of the colon before the rectum)
- **Distal colitis:** involves only the left side of the colon
- **Pancolitis:** affects the entire colon

The Gastrointestinal Tract



WHO GETS ULCERATIVE COLITIS?

Up to 1.4 million Americans have either ulcerative colitis or Crohn's disease. That number is almost evenly split between the two conditions. Here are some quick facts and figures:

- About 30,000 new cases of Crohn's and colitis are diagnosed each year.
- Ulcerative colitis can occur at any age.
- On average, people are diagnosed with ulcerative colitis in their mid-30s.
- More Caucasians than people from other racial groups develop ulcerative colitis.
- The disease tends to occur more often in Jews (largely of Eastern European ancestry) than in people of non-Jewish descent.
- Both ulcerative colitis and Crohn's disease are diseases found mainly in developed countries, more commonly in urban areas rather than rural ones, and more in northern climates than southern ones.

The genetic connection

Researchers have discovered that ulcerative colitis tends to run in certain families.

In fact, up to 20% of people with ulcerative colitis have a first-degree relative (first cousin or closer) with either ulcerative colitis or Crohn's disease. So genetics clearly plays a role, although no specific pattern of inheritance has been identified. That means there is no way to predict which, if any, family members will develop ulcerative colitis or Crohn's disease.

WHAT CAUSES ULCERATIVE COLITIS?

As we noted before, no one knows the exact cause or causes. One thing is clear, though: Nothing that you did made you get ulcerative colitis. You didn't catch it from anyone. It wasn't anything that you ate or drank or smoked. And leading a stressful lifestyle didn't bring it on. So, above all, don't blame yourself!

Now, what are some of the likely causes? Most experts think there is a *multifactorial* explanation. This simply means that it takes a number of circumstances working together to bring about ulcerative colitis—including these top three suspects:

- Genes
- An inappropriate reaction by the body's immune system
- Something in the environment

It's likely that a person inherits one or more genes that make him or her susceptible to ulcerative colitis. Then, something in the environment triggers an abnormal immune response. (Scientists have not yet identified this environmental "trigger." It could be a virus or bacterium, but not necessarily.) Whatever the trigger may be, it prompts the person's immune system to "turn on" and launch an attack against the foreign substance. That's when the inflammation begins. Unfortunately, the immune system doesn't "turn off." So the inflammation continues, damaging the lining of the colon and causing the symptoms of ulcerative colitis.

Nothing that you did made you get ulcerative colitis. Leading a stressful lifestyle didn't bring it on.

WHAT ARE THE SIGNS AND SYMPTOMS OF ULCERATIVE COLITIS?

As the intestinal lining becomes more inflamed and ulcerated, it loses its ability to absorb water from the waste material that passes through the colon. That, in turn, leads to a progressive loosening of the stool—in other words, diarrhea. The damaged intestinal lining also can produce a lot of mucus in the stool. Moreover, ulceration in the lining can cause bleeding so the stool also may be bloody. Eventually, that blood loss may lead to anemia.

Most people with ulcerative colitis experience an urgency to have a bowel movement as well as crampy abdominal pain. The pain may be stronger on the left side. That's because the colon descends on the left.

Together, diarrhea and abdominal pain may result in loss of appetite and subsequent weight loss. These symptoms also can produce fatigue, which is a side effect of anemia as well. Children with ulcerative colitis may fail to develop or grow properly.

Beyond the intestine

In addition to having symptoms in the GI tract, some people may also experience ulcerative colitis in other parts of the body. Signs and symptoms of the disease may be evident in:

- eyes (redness and itchiness)
- mouth (sores)
- joints (swelling and pain)
- skin (bumps and other lesions)
- bones (osteoporosis)
- kidney (stones)
- liver (hepatitis and cirrhosis)—a rare development

All of these are known as *extraintestinal* manifestations of ulcerative colitis because they occur outside of the intestine. In some people, these actually may be the first signs of ulcerative colitis, appearing even before the bowel symptoms. In others, they may occur right before a flare-up of the disease.

People who have had ulcerative colitis for eight to ten years have a higher risk of getting colon cancer. You should talk to your doctor about what you can do to help prevent cancer and lower your risk.

The range of symptoms

Approximately half of all patients with ulcerative colitis have relatively mild symptoms.

However, others may suffer from severe abdominal cramping, bloody diarrhea, nausea, and fever. The symptoms of ulcerative colitis do tend to come and go. In between flare-ups, people may experience no distress at all. These disease-free periods can span months or even years, although symptoms do eventually return. The unpredictable course of ulcerative colitis may make it difficult for doctors to evaluate whether a particular treatment program has been effective or not.

For more information on the management of symptoms and complications related to ulcerative colitis, visit CCFA's Web site at www.ccfa.org.

Managing the symptoms

The medications that your doctor has prescribed are aimed at reducing the intestinal inflammation of ulcerative colitis. However, they may not get rid of all the symptoms that you are experiencing. You may continue to have occasional diarrhea, cramping, nausea, and fever.

Talk to your doctor about which over-the-counter (OTC) medications you can take to help relieve those symptoms. For example, you should be able to take loperamide (Imodium®) on a long-term basis to control the diarrhea. Most anti-gas products and digestive aids are also safe to use, but you should ask your doctor about these first. To reduce fever or ease joint pain, take acetaminophen (Tylenol®) rather than non-steroidal anti-inflammatory drugs (NSAIDs)—such as aspirin, ibuprofen (Advil®, Motrin®), and naproxen (Aleve®), which may irritate your digestive system. Again, make sure to discuss the use of any and all medications with your doctor and be sure to follow the guidelines and instructions on the over-the-counter products that you do take.

But managing symptoms involves more than just medication. Making changes in your diet can help as well. There is no one single diet or eating plan that will do the trick for everyone with ulcerative colitis. Dietary recommendations must be tailored just for you—depending on what part of your intestine is affected and what symptoms you have. Ulcerative colitis varies from person to person and even changes within the same person over time. What worked for your friend with colitis may not work for you. And what worked for you last year may not work now.

Keeping a food diary can be a big help. It allows you to see the connection between what you eat and the symptoms that may follow. If certain foods are causing digestive problems, then try to avoid them. Although no specific foods worsen the underlying inflammation of ulcerative colitis, certain ones tend to aggravate the symptoms. Bearing that in mind, here is some general advice:

- Reduce the amount of greasy or fried foods in your diet, which may cause diarrhea and gas.
- Eat smaller meals at more frequent intervals.
- Limit consumption of milk or milk products if you are lactose intolerant.

- Avoid carbonated beverages.
- Decrease the amount of poorly digestible carbohydrates in your diet to decrease symptoms of gas, bloat, cramps, and diarrhea.
- Restrict your intake of certain high-fiber foods such as nuts, seeds, corn, and popcorn. Because they are not completely digested by the small intestine, these foods may cause diarrhea. That is why a low-fiber, low-residue diet is often recommended. For more information, talk to your dietitian.

MAKING THE DIAGNOSIS

How does a doctor establish the diagnosis of ulcerative colitis? The path toward diagnosis begins by taking a complete family and personal medical history, including full details regarding symptoms. A physical examination is next.

A number of other conditions can cause diarrhea, abdominal pain, and rectal bleeding. That's why your doctor relies on various medical tests to rule out other potential sources, such as infection.

Stool tests can eliminate the possibility of bacterial, viral, and parasitic causes of diarrhea. They also can reveal the presence of blood. Blood tests may be performed to check for anemia, which could suggest bleeding in the colon or rectum.

Blood tests also may detect a high white blood cell count, which indicates the presence of inflammation somewhere in the body.

Looking inside the colon

The next step is an examination of the colon itself, either through a *sigmoidoscopy* or a *colonoscopy*. With a sigmoidoscopy, the doctor inserts a flexible instrument into the rectum and the lower part of the colon. This permits visualization of those areas to see if there is inflammation and, if so, how much. A colonoscopy is similar, but the advantage is that it allows visualization of the entire colon.

Using these techniques, physicians can detect inflammation, bleeding, or ulcers on the colon wall. They also can determine the extent of disease.

During either of these procedures, the examining doctor may take a sample of the colon lining (a biopsy) to send to a pathologist for further study. In that way, ulcerative colitis can be distinguished from other diseases of the colon that cause rectal bleeding — such as Crohn's disease of the colon, diverticular disease, and cancer.

TREATMENT

As we mentioned earlier, there is no medical cure for ulcerative colitis. But there are treatments available that can control it. They work by quieting the abnormal inflammation in the lining of the colon. This permits the colon to heal. It also relieves the symptoms of diarrhea, rectal bleeding, and abdominal pain.

The two basic goals of treatment are to achieve remission (the absence of symptoms) and, once that is accomplished, to maintain remission. Some of the medications used for these two aims may be the same, but they are given in different dosages and for different lengths of time.

There is no "one-size-fits-all" treatment for everyone with ulcerative colitis. The treatment approach must be tailored to the individual because each person's disease is different.

Investigating different approaches may result in increased options for the treatment of inflammatory bowel diseases.

MEDICATIONS FOR ULCERATIVE COLITIS

CLASS OF DRUGS	EXAMPLES	INDICATION	ROUTE OF DELIVERY
Aminosalicylates (5-ASA)	• sulfasalazine *(Azulfadine®)*, • mesalamine *(Asacol®, Lialda®, Pentasa®, Rowasa®)*, • olsalazine *(Dipentum®)*, • balsalazide *(Colazal®)*	Effective for mild-to-moderate episodes of ulcerative colitis. Also useful in preventing relapses of disease.	Oral or rectal
Corticosteroids	• prednisone *(Deltasone®)* • prednisolone *(Pediapred Oral Liquid®, Medrol®)*	For moderate-to-severe ulcerative colitis. Also effective for short-term control of flares.	Oral, rectal, or intravenous (by vein)
Immunomodulators	• azathioprine *(Imuran®, Azasan®)* • 6-MP *(Purinethol®)* • cyclosporine *(Neoral®, Gengraf®, Sandimmune®)* • methotrexate	Indicated for use in people who have not responded adequately to aminosalicylates and corticosteroids. Useful for reducing dependency on corticosteroids. May take up to 3 months to work.	Oral
Biologic therapies	• infliximab *(Remicade®)*	For people with moderate-to-severe ulcerative colitis. Effective for maintaining remission and for tapering people off steroids.	Intravenous (infliximab)
Antibiotics	• metronidazole *(Flagyl®)* • ciprofloxacin *(Cipro®, Proquin®)*	For infections of ulcerative colitis.	Oral or injection

Some medications used to treat ulcerative colitis have been around for years. Others are recent breakthroughs. The most commonly prescribed drugs fall into four basic categories:

- **Aminosalicylates:** These include aspirin-like compounds that contain 5-aminosalicylate acid (5-ASA). Examples are sulfasalazine, mesalamine, olsalazine and balsalazide. These drugs, which can be given either orally or rectally, work at the level of the lining of the GI tract to decrease the inflammation there. They are effective in treating mild-to-moderate episodes of ulcerative colitis. They also are useful in preventing relapses of the disease.

- **Corticosteroids:** These medications, which include prednisone and prednisolone, also affect the body's ability to launch and maintain an inflammatory process. In addition, they work to suppress the immune system. Corticosteroids are used for people with moderate-to-severe disease. They can be administered orally, rectally, or intravenously. They are also effective for short-term control of acute episodes (that is, flare-ups); however, they are not recommended for long-term or maintenance use because of their side effects. If you cannot come off steroids without suffering a relapse of your symptoms, your doctor may need to add some other medications to help manage your disease.

- **Immunomodulators:** These include azathioprine, 6-mercaptopurine (6-MP), and cyclosporine. This class of medications basically overrides the body's immune system so it cannot cause ongoing inflammation. Usually given orally, immunomodulators generally are used in people in whom aminosalicylates and corticosteroids haven't been effective or have been only partially effective. They may be useful in reducing or eliminating dependency on corticosteroids. They also may be effective in maintaining remission in people who haven't responded to other medications given for this purpose. Immunomodulators may take up to three months to begin to work.

- **Biologic therapies:** Biologic therapies are the newest class of drugs used for people suffering from moderate-to-severe ulcerative colitis. These drugs are made from antibodies that bind with certain molecules to block a particular action. The intestinal inflammation of ulcerative colitis is a result of various processes, or "pathways." Because a biologic drug targets a specific pathway, it can help reduce inflammation. That targeted action also keeps side effects to a minimum.

ANTI-TNF

Within the last decade, a class of biologics known as anti-TNF was introduced for use in Crohn's disease, and also ulcerative colitis. These drugs bind to and inactivate tumor necrosis factor (TNF). This is a protein in the immune system that plays a role in inflammation. Although the first anti-TNF drug approved for Crohn's disease was infliximab (Remicade®) in 1998, infliximab was only recently approved for use in ulcerative colitis. It is used for people with moderately-to-severely active ulcerative colitis who haven't responded well to conventional therapy.

In addition, there is a "pipeline" of drugs that are in the very early stages of development. These include many more biologic drugs with different modes of action. Some of the drugs in clinical trials for ulcerative colitis include visilizumab (Nuvion®), and alicaforsen. They are structured to interrupt the out-of-control signaling within different pathways in an immune system that simply won't shut off. By uncovering additional mechanisms, investigators expect to generate increased options for the treatment of chronic inflammatory diseases—including ulcerative colitis.

THE NEXT WAVE

It is a very exciting time in the development of new therapies, as researchers reveal the culprits involved in ulcerative colitis and technology makes it possible to target those culprits to block inflammation. With more than 80 experimental treatments for inflammatory bowel disease in clinical trials, experts predict that a wave of new therapies for ulcerative colitis is on the way. Genetic studies are also expected to yield important insights that will drive the search for new therapies. The hope is that these may be capable of reversing the damage caused by intestinal inflammation and even prevent the disease process from starting in the first place. Finally, because there are several sub-types of ulcerative colitis, there is a great need for an individualized approach to treatment. Accordingly, researchers have begun to evaluate therapies based on cells and proteins derived from the individual patient in order to determine the best treatment course for that person.

This is just an overview of the medications commonly used in the treatment of ulcerative colitis. You can find more specific information about these medications by visiting CCFA's Web site at www.ccfa.org.

SURGERY

Most people with ulcerative colitis respond well to medical treatment and never have to undergo surgery. However, between 25% and 33% of individuals may require surgery at some point.

Sometimes surgery is indicated to take care of various complications related to ulcerative colitis. These include severe bleeding from deep ulcerations, perforation (rupture) of the bowel, and a condition called *toxic megacolon*. Caused by severe inflammation, this is extreme abdominal distension accompanied by fever and constipation. If medical intervention aimed at controlling inflammation and restoring fluid loss doesn't bring about rapid improvement, surgery may become necessary to avoid rupture of the bowel.

Surgery may be considered to remove the entire colon. This is called a *colectomy*. It may be a desirable option when medical therapies no longer control the disease well or when precancerous changes are found in the colon. Unlike Crohn's disease, which can recur after surgery, ulcerative colitis actually is "cured" once the colon is removed.

Surgery may be a desirable option when medical therapies no longer control the disease well.

Depending on a number of factors—including the extent of disease and the person's age and overall health—one of two surgical approaches may be recommended. The first involves the removal of the entire colon and rectum, with the creation of an ileostomy (an opening on the abdomen through which wastes are emptied into a pouch).

Today, many people can take advantage of new surgical techniques that offer another option. This procedure, called an *ileoanal pouch anal anastomosis (IPAA)*, also calls for removal of the colon, but it avoids an ileostomy. By creating an internal pouch from the small bowel and attaching it to the anal sphincter muscle, the surgeon preserves bowel function and eliminates the need for an external ostomy appliance.

For more information on surgery in ulcerative colitis, see CCFA's Web site at www.ccfa.org.

THE ROLE OF NUTRITION

You may wonder if eating any particular foods caused or contributed to your ulcerative colitis. The answer is "no." However, once the disease has developed, paying some attention to diet may help you reduce your symptoms, replace lost nutrients, and promote healing. For example, when your disease is active, you may find that bland, soft foods may cause less discomfort than spicy or high-fiber foods. Smaller, more frequent meals also may help.

Maintaining proper nutrition is important in the management of ulcerative colitis. Good nutrition is essential in any chronic disease, but especially in this illness. Abdominal pain and fever can cause loss of appetite and weight loss. Diarrhea and rectal bleeding can rob the body of fluids, nutrients, and electrolytes. These are minerals in the body that must remain in proper balance for the body to function properly.

But that doesn't mean that you must eat certain foods or avoid others. Except for restricting milk products in lactose-intolerant people, or restricting caffeine when severe diarrhea occurs, most doctors simply recommend a well-balanced diet to prevent nutritional deficiency. A healthy diet should contain a variety of foods from all food groups. Meat, fish, poultry, and dairy products (if tolerated) are sources of protein; bread, cereal, starches, fruits, and vegetables are sources of carbohydrates; margarine and oils are sources of fat. A dietary supplement, like a multivitamin, can help fill the gaps.

Good nutrition is essential. You may find that smaller, more frequent meals may help.

Probiotics and prebiotics

Researchers have been looking at other forms of intestinal protection for people with ulcerative colitis and Crohn's disease. That's where probiotics and prebiotics come in.

What are these substances? *Probiotics*, also known as "beneficial" or "friendly" bacteria, are microscopic organisms that assist in maintaining a healthy GI tract. Approximately 400 different types of good bacteria live within the human digestive system, where they keep the growth of harmful bacteria in check. A proper balance between good and bad bacteria is key. If beneficial bacteria drop in number or the balance is otherwise thrown off, that's when harmful bacteria can overgrow—causing diarrhea and other digestive problems. In people with already damaged GI tracts, like those with ulcerative colitis, symptoms may be particularly severe. Mounting evidence suggests the use of probiotics—available in capsules, powders, liquids, and wafers—may represent another therapeutic option for people with IBD, particularly in helping to maintain remission.

Prebiotics are non-digestible food ingredients that provide nutrients to allow beneficial bacteria in the gut to multiply. They also stimulate the growth of probiotics.

More information on diet and nutrition in ulcerative colitis can be found at CCFA's Web site at www.ccfa.org.

THE ROLE OF STRESS AND EMOTIONAL FACTORS

Some people think it takes a certain personality type to develop ulcerative colitis or other inflammatory bowel disease. They're wrong. But, because body and mind are so closely interrelated, emotional stress can influence the *symptoms* of ulcerative colitis—or, for that matter, any chronic illness.

Although the disease occasionally recurs after a person has been experiencing emotional problems, there is no proof that stress *causes* ulcerative colitis.

It is much more likely that the emotional distress that people sometimes feel is a reaction to the symptoms of the disease itself. Individuals with ulcerative colitis should receive understanding and emotional support from their families and doctors. Although formal psychotherapy usually isn't necessary, some people are helped considerably by speaking with a therapist who is knowledgeable about IBD or about chronic illness in general. CCFA offers local support groups to help patients and their families cope with ulcerative colitis and Crohn's disease.

Plan ahead

You'll learn that there are numerous strategies that can make living with ulcerative colitis easier. Coping techniques for dealing with the disease may take many forms. For example, attacks of diarrhea or abdominal pain may make people fearful of being in public places. But that isn't necessary. All it takes is some practical advance planning. Find out where the restrooms are in restaurants, shopping areas, theaters, and on public transportation. Carrying along extra underclothing or toilet paper is another smart maneuver. When venturing further away or for longer periods of time, speak to your doctor first. Travel plans should include a large enough supply of your medication, its generic name in case you run out or lose it, and the names of doctors in the area you will be visiting.

LIVING A NORMAL LIFE WITH ULCERATIVE COLITIS

Perhaps the most difficult period for you is right now, when you have just learned you have this chronic illness called ulcerative colitis. As time goes on, though, this fact will not always occupy the top spot on your mind. In the meantime, don't hide your condition from family, friends, and co-workers. Discuss it with them and let them help and support you.

Try to go about your daily life as normally as possible, pursuing activities as you did before your diagnosis. There's no reason for you to sit out on things that you have always enjoyed or have dreamed of doing one day. Learn coping strategies from others—your local CCFA chapter offers support groups as well as informational meetings—and share what you know with others, too. Follow your doctor's instructions about taking medication (even when you are feeling perfectly well) and maintain a positive outlook. That's the basic—and best—prescription. While ulcerative colitis is a serious chronic disease, it is not a fatal one. There's no doubt that living with this illness is challenging—you have to take medication and, occasionally, may be hospitalized. But it's important to remember that most people with ulcerative colitis are able to lead rich and productive lives.

Remember, also, that taking maintenance medication can significantly decrease flare-ups of ulcerative colitis. In between disease flares, most people are free of symptoms and feel well.

HOPE FOR THE FUTURE

Laboratories all over the world are devoted to the scientific investigation of ulcerative colitis. That's good news when it comes to the development of new therapies for this disease. CCFA-sponsored research has led to huge strides in the fields of immunology, the study of the body's immune defense system; microbiology, the study of microscopic organisms with the power to cause disease; and genetics. Through CCFA's continuing research efforts, much more will be learned and eventually a cure will be found.

For more brochures and fact sheets on Crohn's disease and ulcerative colitis, please call CCFA at 888.MY.GUT.PAIN, or visit us on the Internet at www.ccfa.org.

KNOWLEDGE IS POWER!

Find the answers you need to help control your Crohn's or ulcerative colitis by joining CCFA.

Discover great ways to manage your disease and work for a cure! To join the Crohn's & Colitis Foundation of America, complete and send the application on the next page today.

By joining CCFA, you'll get:

- *Take Charge,* our national magazine
- *Under the Microscope,* our newsletter with research updates
- News, educational programs, and supportive services from your local CCFA chapter
- Discounts on select programs and merchandise

Established in 1967, the Crohn's & Colitis Foundation of America, Inc. (CCFA) is the only private, national nonprofit organization dedicated to finding the cure for IBD. Our mission is to fund research; provide educational resources for patients and their families, medical professionals, and the public; and to furnish supportive services for people with Crohn's or colitis.

In addition to supporting these key programs, CCFA donations are vital to our advocacy efforts. CCFA has played a crucial role in obtaining increased funding for IBD research at the National Institutes of Health, and in advancing legislation that will improve the lives of patients nationwide.

Start getting the latest information on symptom management, research findings and government legislation that can help you. Join CCFA today by calling (800) 932-2423, visiting www.ccfa.org, or completing and sending the application on the next page to:

Crohn's & Colitis Foundation of America
Attn: Membership
386 Park Avenue South
17th Floor
New York, NY 10016

"Over and over, CCFA has helped me find the strength I need to go on. CCFA's local network of people go through what I go through; they also meet the challenges I face every day with ulcerative colitis."

Join CCFA

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NOTES


FORWARD

Crohn's & Colitis Foundation of America
Wisconsin Chapter
1126 S. 70th Street Ste. S210-A
West Allis, WI 53214
Phone:414-475-5520 or 877-586-5588

CROHN'S & COLITIS
FOUNDATION OF AMERICA

Our Mission:

To cure and prevent Crohn's disease and ulcerative colitis through research, and to improve the quality of life of children and adults affected by these digestive diseases through education and support.

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www.ccfa.org

National Office

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17th Floor
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CROHN'S & COLITIS
FOUNDATION OF AMERICA

Living with Crohn's Disease

UNDERSTANDING THE DIAGNOSIS

Your doctor has just told you that you have a disease called Crohn's disease. Quite possibly, you have never even *heard* of this condition before. (Most people, in fact, are unfamiliar with Crohn's disease.) And now you have it. And, to make matters worse, your doctor has said that Crohn's disease doesn't go away.

If you feel overwhelmed and scared right now, that's only natural. You probably have a ton of questions, starting with "Just what *is* Crohn's disease?" But you're also wondering how you got it and, more important, how it will affect you—both now and down the road. For example, you'll want to know:

- Will I be able to work, travel, and exercise?
- Should I be on a special diet?
- Will I need surgery?
- How will Crohn's disease change my life?

That's the purpose of this brochure: to answer those questions and to walk you through the key points about Crohn's disease and what you may expect in the future. You won't become an expert overnight, but gradually you'll learn more and more. And the more you know, the better you'll be able to cope with the disease and become an active member of your own healthcare team.

WHAT IS CROHN'S DISEASE?

The disease is named after Dr. Burrill B. Crohn, who published a landmark paper with colleagues Oppenheimer and Ginzburg in 1932, describing the features of what is known today as Crohn's disease. Crohn's and a related disease, ulcerative colitis, are the two main disease categories that belong to a larger group of illnesses called *inflammatory bowel disease (IBD)*.

Both Crohn's disease and ulcerative colitis cause diarrhea (sometimes bloody), as well as abdominal pain. Because the symptoms of these two illnesses are so similar, it is sometimes difficult for doctors to make a definitive diagnosis. In fact, approximately 10% of cases are unable to be pinpointed as either Crohn's disease or ulcerative colitis.

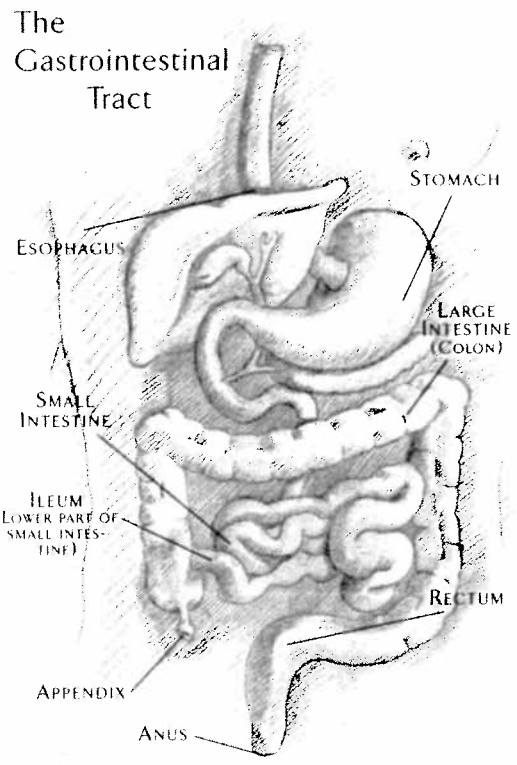
Ulcerative colitis is limited to the colon (also called the large intestine). Crohn's disease may affect any part of the gastrointestinal (GI) tract from the mouth to the anus. However, Crohn's may also include most of the small intestine (the ileum) and the beginning of the colon. All layers of the intestine may be involved, and there can be normal healthy bowel in between patches of diseased bowel. These are the so-called "skip" areas. In contrast, ulcerative colitis moves in a more even and continuous distribution and affects only the superficial layers of the colon.

What does "chronic" mean?

No one knows exactly what causes either Crohn's disease or ulcerative colitis. Also, no one can predict how the disease — once it is diagnosed — will affect a particular person. Some people go for years without having any symptoms, while others have more frequent flare-ups of disease. However, one thing is sure: Crohn's disease — like ulcerative colitis — is a chronic condition. Chronic conditions are ongoing situations. They can be controlled with treatment but cannot be cured. That means that the disease is long-term, but it does *not* mean that it is fatal. It isn't. Most people who have Crohn's disease lead full and productive lives.

A BRIEF INTRODUCTION TO THE GI TRACT

Most of us aren't very familiar with the gastrointestinal (GI) tract, even though it occupies a lot of "real estate" in our bodies. Here's a quick tour:



The GI tract actually starts at the mouth. It follows a twisting and turning course and ends, many yards later, at the rectum. In between are a number of organs that all play a part in processing food and transporting it through the body. The first is the esophagus, a narrow tube that connects the mouth to the stomach. After that comes the stomach itself. Moving downward, the next organ is the small intestine. That leads to the colon, or large intestine, which connects to the rectum.

Types of Crohn's disease and associated symptoms

The symptoms and potential complications of Crohn's disease differ, depending on what part of the GI tract is inflamed. That's why it is important for you to know which part of your intestine is affected by Crohn's disease. Your doctor also may refer to your illness by various names based on the main area involved. The following are five types of Crohn's disease:

- ***Ileocolitis:*** The most common form of Crohn's, affecting the ileum and colon. Symptoms include diarrhea and cramping or pain in the right lower part or middle of the abdomen. Often accompanied by significant weight loss.
- ***Ileitis:*** Affects the ileum. Symptoms are the same as ileocolitis. Complications may include an inflammatory abscess (a collection of pus) in the right lower quadrant of the abdomen or fistulas. Fistulas are tunnels leading from one loop of intestine to the other, or between the intestine and another part of the body.
- ***Gastroduodenal Crohn's disease:*** Affects the stomach and duodenum (the first part of the small intestine). Symptoms include loss of appetite, weight loss, and nausea. Vomiting may indicate that narrowed segments of the bowel are obstructed.

The more you know, the better you'll be able to cope with the disease.

- ***Jejunoileitis:*** Produces patchy areas of inflammation in the jejunum (upper half of the small intestine). Symptoms include abdominal pain, ranging from mild to intense, and cramps following meals, as well as diarrhea. Fistulas (see "Ileitis") may also form.
- ***Crohn's (granulomatous) colitis:*** Affects the colon only. Symptoms include diarrhea, rectal bleeding, and disease around the anus (abscess, fistulas, ulcers). Skin lesions and joint pains are more common in this form of Crohn's than in others.

WHO GETS CROHN'S DISEASE?

Up to 1.4 million Americans have either Crohn's disease or ulcerative colitis. That number is almost evenly split between the two conditions. Here are some quick facts and figures:

- About 30,000 new cases of Crohn's and colitis are diagnosed each year.
- Most people diagnosed with Crohn's disease are young, between the ages of 15 and 35. However, Crohn's disease can also occur in people who are 70 or older and in young children as well. In fact, 10% of those affected—or an estimated 140,000—are under the age of 18.
- Males and females appear to be affected equally.
- More Caucasians than people from other racial groups develop Crohn's disease.
- The disease tends to occur more often in Jews (largely of Eastern European ancestry) than in people of non-Jewish descent.
- Both Crohn's disease and ulcerative colitis are diseases found mainly in developed countries, more commonly in urban areas rather than rural ones, and more in northern climates than in southern ones.

The genetic connection

Researchers have discovered that Crohn's disease tends to run in certain families. In fact, up to 20% of people with Crohn's disease have a first-degree relative (first cousin or closer) with either Crohn's disease or ulcerative colitis.

So genetics clearly plays a role. Investigators have been working actively for some time to find a link to specific genes that control the transmission of Crohn's disease. In the late 1990s, two independent teams of researchers made a major breakthrough when they identified the first gene for Crohn's disease. They discovered an abnormal mutation or alteration in a gene known as NOD2. This mutation, which limits the ability to fight bacteria, occurs twice as frequently in Crohn's patients as in the general population. Currently, there's no method to screen people for this gene. And there is no way to predict which, if any, family members will develop Crohn's disease. It also appears that more than one gene may be involved. Thanks to new technologies, though, researchers may soon close in on those genes.

WHAT CAUSES CROHN'S DISEASE?

As we noted before, no one knows the exact cause or causes. One thing is clear, though. Nothing that you did made you get Crohn's disease. You didn't catch it from anyone. It wasn't anything that you ate or drank or smoked. And leading a stressful lifestyle didn't bring it on. So, above all, don't blame yourself!

Now, what are some of the likely causes? Most experts think there is a *multifactorial* explanation. This simply means that it takes a number of circumstances working together to bring about Crohn's disease—including these top three suspects:

- Genes
- An inappropriate reaction by the immune system
- Something in the environment

It's likely that a person inherits one or more genes that make him or her susceptible to Crohn's disease. Then, something in the environment triggers an abnormal immune response. (Scientists have not yet identified this environmental "trigger." It could be a virus or bacterium, but not necessarily.) Whatever the trigger may be, it prompts the person's immune system to "turn on" and launch an attack against the foreign substance. That's when the inflammation begins. Unfortunately, the immune system doesn't "turn off." So the inflammation continues, damaging the lining of the intestines and causing the symptoms of Crohn's disease.

WHAT ARE THE SIGNS AND SYMPTOMS OF CROHN'S DISEASE?

Persistent diarrhea (loose, watery, or frequent bowel movements), crampy abdominal pain, fever, and, at times, rectal bleeding: These are the hallmark symptoms of Crohn's disease, but they vary from person to person and may change over time. Loss of appetite and subsequent weight loss also may occur. Fatigue is another common complaint. Children who have Crohn's disease may suffer delays in both growth and sexual development.

Some patients may develop tears (fissures) in the lining of the anus, which may cause pain and bleeding, especially during bowel movements. Inflammation may also cause a fistula to develop. A fistula is a tunnel that leads from one loop of intestine to another, or that connects the intestine to the bladder, vagina, or skin. Fistulas occur most commonly around the anal area. If this complication arises, you may notice drainage of mucus, pus, or stool from this opening.

Crohn's disease runs in certain families. So genetics clearly plays a role.

Symptoms may range from mild to severe. Because Crohn's is a chronic disease, patients will go through periods in which the disease flares up, is active, and causes symptoms. These episodes are followed by times of remission—periods in which symptoms disappear or decrease and good health returns. In general, though, people with Crohn's disease lead full, active, and productive lives.

Beyond the intestine

In addition to having symptoms in the GI tract, some people also may experience Crohn's disease in other parts of the body. Signs and symptoms of the disease may be evident in:

- eyes (redness and itchiness)
- mouth (sores)
- joints (swelling and pain)
- skin (bumps and other lesions)
- bones (osteoporosis)
- kidney (stones)
- liver (hepatitis and cirrhosis)—a rare development

All of these are known as *extraintestinal* manifestations of Crohn's disease because they occur outside of the intestine. In some people these may actually be the first signs of Crohn's disease, appearing even before the bowel symptoms. In others, they may occur right before a flare-up of the disease.

The range of symptoms

Approximately half of all patients with Crohn's disease have relatively mild symptoms. However, others may suffer from severe abdominal cramping, bloody diarrhea, nausea, and fever. The symptoms of Crohn's disease do tend to come and go. In between flare-ups, people may experience no distress at all. These disease-free periods can span months or even years, although symptoms do eventually return. The unpredictable course of Crohn's disease may make it difficult for doctors to evaluate whether a particular course of treatment has been effective or not.

For more information on the management of symptoms and complications related to Crohn's disease, visit CCFA's Web site at www.ccfa.org.

Your doctor can help you decide on the best treatment option for your Crohn's disease.

Managing the symptoms

The medications that your doctor has prescribed are aimed at reducing the intestinal inflammation of Crohn's disease. However, they may not get rid of all the symptoms that you are experiencing. You may continue to have occasional diarrhea, cramping, nausea, and fever.

Talk to your doctor about which over-the-counter (OTC) medications you can take to help relieve those symptoms. For example, you should be able to take loperamide (Imodium®) on a long-term basis to control the diarrhea. Most anti-gas products and digestive aids are also safe to use, but you should ask your doctor about these first. To reduce fever or ease joint pain, take acetaminophen (Tylenol®) rather than non-steroidal anti-inflammatory drugs (NSAIDs)—such as aspirin, ibuprofen (Advil®, Motrin®), and naproxen (Aleve®), which may irritate your digestive system. Again, make sure to discuss the use of any and all medications with your doctor and be sure to follow the guidelines and instructions on the over-the-counter products that you do take.

But managing symptoms involves more than just medication. Making changes in your diet can help as well. There is no one single diet or eating plan that will do the trick for everyone with Crohn's disease. Dietary recommendations must be tailored just for you—depending on what part of your intestine is affected and what symptoms you have. Crohn's disease varies from person to person and even changes within the same person over time. What worked for your friend with Crohn's may not work for you. And what worked for you last year may not work now. Keeping a food diary can be a big help. It allows you to see the connection between what you eat and the symptoms that may follow. If certain foods are causing digestive problems, then try to avoid them. Although no specific foods worsen the underlying inflammation of Crohn's disease, certain ones tend to aggravate the symptoms. Bearing that in mind, here is some general advice:

- Reduce the amount of greasy or fried foods in your diet, which may cause diarrhea and gas.
- Eat smaller meals at more frequent intervals.
- Limit consumption of milk or milk products if you are lactose intolerant.
- Avoid carbonated beverages.
- Decrease the amount of poorly digestible carbohydrates in your diet to decrease symptoms of gas, bloat, cramps, and diarrhea.
- Restrict your intake of certain high-fiber foods such as nuts, seeds, corn, and popcorn. Because they are not completely digested by the small intestine, these foods may cause diarrhea. That is why a low-fiber, low-residue diet is often recommended. For more information, talk to your dietitian.

MAKING THE DIAGNOSIS

How does a doctor establish the diagnosis of Crohn's disease? The path toward diagnosis begins by taking a complete family and personal medical history, including full details regarding the symptoms described above. A physical examination is next.

A number of other conditions can cause diarrhea and abdominal pain, even rectal bleeding. That's why your doctor relies on various medical tests to rule out other sources, such as infection. Stool tests can eliminate the possibility of bacterial, viral, and parasitic causes of diarrhea. They also can reveal the presence of blood. Blood tests may be performed to check for anemia, which could suggest bleeding in the colon or rectum. Blood tests also may detect a high white blood cell count, which indicates the presence of inflammation somewhere in the body. However, Crohn's disease cannot be diagnosed via a blood test. Researchers have been investigating a number of markers in the blood that may be elevated in people with Crohn's, but these haven't yet been accepted as sufficiently accurate to allow doctors to make a definitive diagnosis.

The inflammation that marks Crohn's disease is often a chronic cycle.

Looking inside the colon

The next step is an examination of the colon itself, either through a *sigmoidoscopy* or a *colonoscopy.* With a sigmoidoscopy, the doctor inserts a flexible instrument into the rectum and the lower part of the colon. This permits visualization of those areas to see if there is inflammation and, if so, how much. A colonoscopy is similar, but the advantage is that it allows visualization of the entire colon.

Using these techniques, your physician can detect inflammation, bleeding, or ulcers on the colon wall. They also can determine the extent of disease. During either of these procedures, the examining doctor may take a sample of the colon lining (a biopsy) to send to a pathologist for further study. In that way, Crohn's disease can be distinguished from other diseases of the colon that cause rectal bleeding—such as ulcerative colitis, diverticular disease, and cancer.

MEDICATIONS FOR CROHN'S DISEASE

CLASS OF DRUGS	EXAMPLES	INDICATION	ROUTE OF DELIVERY
Aminosalicylates (5-ASA)	• sulfasalazine *(Azulfadine®)*, • mesalamine *(Asacol®, Lialda®, Pentasa®, Rowasa®)*, • olsalazine *(Dipentum®)*, • balsalazide *(Colazal®)*	Effective for mild-to-moderate episodes of Crohn's disease. Also useful in preventing relapses of disease.	Oral or rectal
Corticosteroids	• budesonide *(Entocort®EC)* • prednisone *(Deltasone®)* • prednisolone *(Pediapred Oral Liquid®, Medrol®)*	For mild to moderate Crohn's disease. A newer type of non-systemic steroid For moderate-to-severe Crohn's disease. Also effective for short-term control of flares.	Oral Oral, rectal, or intravenous (by vein)
Immunomodulators	• azathioprine *(Imuran®, Azasan®)* • 6-MP *(Purinethol®)* • cyclosporine *(Neoral®, Gengraf®, Sandimmune®)* • methotrexate	Indicated for use in people who have not responded adequately to aminosalicylates and corticosteroids. Useful for reducing dependency on corticosteroids. May take up to 3 months to work.	Oral
Biologic therapies	• infliximab *(Remicade®)* • adalimumab *(Humira®)*	For people with moderate-to-severe Crohn's disease. Effective for maintaining remission and for tapering people off steroids.	Intravenous (infliximab) Injection under the skin (adalimumab)
Antibiotics	• metronidazole *(Flagyl®)* • ciprofloxacin *(Cipro®, Proquin®)*	For infections of Crohn's disease, such as abscesses.	Oral or injection

TREATMENT

As we mentioned earlier, there is no medical cure for Crohn's disease. But there are treatments available that can control it. They work by quieting the abnormal inflammation in the lining of the intestines. This permits the bowel to heal. It also relieves the symptoms of diarrhea, rectal bleeding, and abdominal pain.

The two basic goals of treatment are to achieve remission (the absence of symptoms) and, once that is accomplished, to maintain remission. Some of the medications used for these two aims may be the same, but they are given in different dosages and for different lengths of time. There is no "one-size-fits-all" treatment for everyone with Crohn's disease. The treatment approach must be tailored to the individual because each person's disease is different.

Some medications used to treat Crohn's disease have been around for years. Others are recent breakthroughs. The most commonly prescribed drugs fall into five basic categories:

- **Aminosalicylates:** These include aspirin-like compounds that contain 5-aminosalicylate acid (5-ASA). Examples are sulfasalazine, mesalamine, olsalazine and balsalazide. These drugs, which can be given either orally or rectally, work at the level of the lining of the GI tract to decrease the inflammation there. They are effective in treating mild-to-moderate episodes of Crohn's disease. They also are useful in preventing relapses of the disease.
- **Corticosteroids:** These medications, which include prednisone and prednisolone, also affect the body's ability to launch and maintain an inflammatory process. In addition, they work to suppress the immune system. Corticosteroids are used for people with moderate-to-severe Crohn's disease. They can be administered orally, rectally, or intravenously. They are also effective for short-term control of acute episodes (that is, flare-ups); however, they are not recommended for long-term or maintenance use because of their side effects. Budesonide is a nonsystemic steroid used to treat mild-to-moderate Crohn's disease. Budesonide causes fewer side effects. If you cannot come off steroids without suffering a relapse of your symptoms, your doctor may need to add some other medications to help manage your disease.
- **Immunomodulators:** These include azathioprine, 6-mercaptopurine (6-MP), and cyclosporine. This class of medications basically overrides the body's immune system so it cannot cause ongoing inflammation. Usually given orally, immunomodulators generally are used in people in whom aminosalicylates and corticosteroids haven't been effective or have been only partially effective. They may be useful in reducing or eliminating dependency on corticosteroids. They also may be effective in maintaining remission in people who haven't responded to other medications given for this purpose. Immunomodulators may take up to three months to begin to work.
- **Antibiotics:** Metronidazole, ciprofloxacin, and other antibiotics may be used when infections, such as abscesses, occur in Crohn's disease.

Investigating different approaches may result in increased options for the treatment of inflammatory bowel diseases.

- **Biologic therapies for IBD:** Biologic therapies are the newest class of drugs used for people suffering from moderate-to-severe Crohn's disease. These drugs are made from antibodies that bind with certain molecules to block a particular action. The intestinal inflammation of Crohn's disease is a result of various processes, or "pathways." Because a biologic drug targets a specific pathway, it can help reduce inflammation. That targeted action also keeps side effects to a minimum.

  Other biologic drugs are currently undergoing clinical trials for Crohn's disease. For more information on drugs in clinical trials, visit www.ccfa.org/trials.

Anti-TNF

Within the last decade, a class of biologics known as anti-TNF was introduced for use in Crohn's disease. These drugs bind to and inactivate tumor necrosis factor (TNF). This is a protein in the immune system that plays a role in inflammation. The first anti-TNF drug approved for Crohn's disease was infliximab (Remicade®). It is used for people with moderately-to-severely active Crohn's disease who haven't responded well to conventional therapy. Another agent, adalimumab (Humira®), was recently approved for use in Crohn's disease. Yet another anti-TNF, certolizumab pegol (Cimzia®), is currently being investigated for people with Crohn's disease.

Adhesion Molecule Inhibitors

A recent development in biologic therapy is the development of adhesion molecule inhibitors. Their mechanism of action is different from the anti-TNF agents. Adhesion molecule inhibitors work by binding to particular cells in the bloodstream that are key players in inflammation. Natalizumab (Tysabri®), already approved for multiple sclerosis, is one such therapy currently under investigation for the treatment of Crohn's disease.

In addition, there is a "pipeline" of drugs that are in the very early stages of development. These include many more biologic drugs with different modes of action. They are structured to interrupt the out-of-control signaling within different pathways in an immune system that simply won't shut off. By uncovering additional mechanisms, investigators expect to generate increased options for the treatment of chronic inflammatory diseases—including Crohn's disease.

The Next Wave

It is a very exciting time in the development of new therapies, as researchers reveal the culprits involved in Crohn's disease and technology makes it possible to target those culprits to block inflammation. With more than 80 experimental treatments in clinical trials, experts predict that a wave of new therapies for Crohn's disease is on the way. Genetic studies are also expected to yield important insights that will drive the search for new therapies. The hope is that these may be capable of reversing the damage caused by intestinal inflammation and even prevent the disease process from starting in the first place. Finally, because there are several sub-types of Crohn's disease, there is a great need for an individualized approach to treatment. Accordingly, researchers have begun to evaluate therapies based on cells and proteins derived from the individual patient in order to determine the best treatment course for that person.

This is just an overview of the medications commonly used in the treatment of Crohn's disease. You can find more specific information about these medications by visiting CCFA's Web site at www.ccfa.org.

Biologic therapy options may help Crohn's disease patients achieve and maintain remission.

SURGERY

Many individuals with Crohn's disease respond well to medical treatment and never have to undergo surgery. However, two-thirds to three-quarters of people will require surgery at some point during their lives.

Treatment involves achieving and maintaining remission. Surgery can also help.

Surgery may become necessary in Crohn's disease when medications are no longer effective in controlling symptoms. It may also be performed to repair a fistula or fissure. Another indication for surgery is the presence of an intestinal obstruction or other complication, such as an intestinal abscess. In most cases, the diseased segment of bowel and any associated abscess is removed. This is called a resection. The two ends of healthy bowel are then joined together in a procedure called an anastomosis. While resection and anastomosis may allow many symptom-free years, this surgery is not considered a cure for Crohn's disease, because the disease frequently recurs at or near the site of anastomosis.

An ileostomy also may be required when surgery is performed for Crohn's disease of the colon. After surgeons remove the colon, they bring the small bowel to the skin so that waste products may be emptied into a pouch attached to the abdomen. This procedure is needed if the rectum is diseased and cannot be used for an anastomosis.

The overall goal of surgery in Crohn's disease is to conserve bowel and return the individual to the best possible quality of life. Unlike surgery for ulcerative colitis, though, surgery for Crohn's disease does not represent a cure.

For more information on surgery in Crohn's disease, see CCFA's Web site at www.ccfa.org.

THE ROLE OF NUTRITION

You may wonder if eating any particular foods caused or contributed to Crohn's disease. The answer is no. However, once the disease has developed, paying some attention to diet may help you reduce the symptoms, replace lost nutrients, and promote healing. For example, when your disease is active, you may find that bland, soft foods may cause less discomfort than spicy or high-fiber foods. Smaller, more frequent meals also may help.

Maintaining proper nutrition is important in the management of Crohn's disease. Good nutrition is essential in any chronic disease but especially in this illness. Abdominal pain and fever can cause loss of appetite and weight loss. Diarrhea and rectal bleeding can rob the body of fluids, nutrients, and electrolytes. These are minerals in the body that must remain in proper balance for the body to function properly.

But that doesn't mean that you must eat certain foods or avoid others. Except for restricting milk products in lactose-intolerant people or restricting caffeine when severe diarrhea occurs, most doctors simply recommend a well-balanced diet to prevent nutritional deficiency. A healthy diet should contain a variety of foods from all food groups. Meat, fish, poultry, and dairy products (if tolerated) are sources of protein; bread, cereal, starches, fruits, and vegetables are sources of carbohydrates; margarine and oils are sources of fat. A dietary supplement, like a multivitamin, can help fill the gaps.

Probiotics and prebiotics

Researchers have been looking at other forms of intestinal protection for people with Crohn's disease. That's where probiotics and prebiotics come in.

What are these substances? *Probiotics,* also known as "beneficial" or "friendly" bacteria, are microscopic organisms that assist in maintaining a healthy GI tract. Approximately 400 different types of good bacteria live within the human digestive system, where they keep the growth of harmful bacteria in check. A proper balance between good and bad bacteria is key. If beneficial bacteria become depleted or the balance is otherwise thrown off, that's when harmful bacteria can overgrow — causing diarrhea and other digestive problems. In people with already damaged GI tracts, like those with Crohn's disease, symptoms may be particularly severe. Mounting evidence suggests the use of probiotics — available in capsules, powders, liquids, and wafers — may represent another therapeutic option for people with IBD, particularly in helping to maintain remission.

Prebiotics are non-digestible food ingredients that provide nutrients that allow beneficial bacteria in the gut to multiply. They also stimulate the growth of probiotics.

Further information on diet and nutrition in Crohn's disease can be found on CCFA's Web site at www.ccfa.org.

THE ROLE OF STRESS AND EMOTIONAL FACTORS

Some people think it takes a certain personality type to develop Crohn's disease or other inflammatory bowel diseases. They're wrong. But, because body and mind are so closely interrelated, emotional stress can influence the *symptoms* of Crohn's disease — or, for that matter, any chronic illness. Although the disease occasionally recurs after a person has been experiencing emotional problems, there is no proof that stress *causes* Crohn's disease.

It is much more likely that the emotional distress that people sometimes feel is a reaction to the symptoms of the disease itself. Individuals with Crohn's disease should receive understanding and emotional support from their families and doctors. Although formal psychotherapy is generally not necessary, some people are helped considerably by speaking with a therapist who is knowledgeable about IBD or about chronic illness in general. CCFA offers local support groups to help patients and their families cope with Crohn's disease and ulcerative colitis.

Plan ahead

You'll learn that there are numerous strategies that can make living with Crohn's disease easier. Coping techniques for dealing with the disease may take many forms. For example, attacks of diarrhea or abdominal pain may make people fearful of being in public places. But that isn't necessary. All it takes is some practical advance planning. Find out where the restrooms are in restaurants, shopping areas, theaters, and on public transportation. Carrying along extra underclothing or toilet paper is another smart maneuver. When venturing further away or for longer periods of time, speak to your doctor first. Travel plans should include a large enough supply of your medication, its generic name in case you run out or lose it, and the names of doctors in the area you will be visiting.

LIVING A NORMAL LIFE WITH CROHN'S DISEASE

Perhaps the most difficult period for you is right now, when you have just learned you have this chronic illness called Crohn's disease. As time goes on, though, this fact will not always occupy the top spot on your mind. In the meantime, don't hide your condition from family, friends, and co-workers. Discuss it with them and let them help and support you.

Try to go about your daily life as normally as possible, pursuing activities as you did before your diagnosis. There's no reason for you to sit out on things that you have always enjoyed or have dreamed of doing one day. Learn coping strategies from others—your local CCFA chapter offers support groups as well as informational meetings—and share what you know with others, too. Follow your doctor's instructions about taking medication (even when you are feeling perfectly well) and maintain a positive outlook. That's the basic—and best—prescription.

While Crohn's disease is a serious chronic disease, it is not a fatal one. There's no doubt that living with this illness is challenging—you have to take medication and, occasionally, may be hospitalized. But it's important to remember that most people with Crohn's disease are able to lead rich and productive lives.

Remember, also, that taking maintenance medication can significantly decrease flare-ups of Crohn's disease. In between disease flares, most people are free of symptoms and feel well.

HOPE FOR THE FUTURE

Laboratories all over the world are devoted to the scientific investigation of Crohn's disease. That's good news when it comes to the development of new therapies for this disease. CCFA-sponsored research has led to huge strides in the fields of immunology, the study of the body's immune defense system; microbiology, the study of microscopic organisms with the power to cause disease; and genetics. Through CCFA's continuing research efforts, much more will be learned and eventually a cure will be found.

For more brochures and fact sheets on Crohn's disease and ulcerative colitis, please call CCFA at 888.MY.GUT.PAIN, or visit us on the Internet at www.ccfa.org.

KNOWLEDGE IS POWER!

Find the answers you need to help control your Crohn's or ulcerative colitis by joining CCFA.

Discover great ways to manage your disease and work for a cure! To join the Crohn's & Colitis Foundation of America, complete and send the application on the next page today.

By joining, you'll get:

- *Take Charge,* our national magazine
- *Under the Microscope,* our newsletter with research updates
- News, educational programs, and supportive services from your local CCFA chapter
- Discounts on select programs and merchandise

Established in 1967, the Crohn's & Colitis Foundation of America, Inc. (CCFA) is the only private, national nonprofit organization dedicated to finding the cure for IBD. Our mission is to fund research; provide educational resources for patients and their families, medical professionals, and the public; and to furnish supportive services for people with Crohn's or colitis.

In addition to supporting these key programs, CCFA donations are vital to our advocacy efforts. CCFA has played a crucial role in obtaining increased funding for IBD research at the National Institutes of Health, and in advancing legislation that will improve the lives of patients nationwide.

Start getting the latest information on symptom management, research findings and government legislation that can help you. Join CCFA today by calling 800-932-2423, visiting www.ccfa.org, or completing and sending the application on the next page to:

Crohn's & Colitis Foundation of America
Attn: Membership
386 Park Avenue South
17th Floor
New York, NY 10016

Join CCFA

YES, I want to be part of the solution by supporting CCFA.

PLEASE CHECK ONE:

- ❑ Individual..... $30
- ❑ Family $60
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- ❑ Contributing $250
- ❑ Patron $500
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(Minimum: $30.00)

Name: _____

Address: _____

City: _____ State: Zip: _____

Home #: _____

Email address: _____

Optional & Confidential (For CCFA use only):
CCFA does not sell, lend or exchange its member information with anyone. All information is kept strictly confidential.

Employer/
Business Name: _____

Address: _____

City: _____ State: Zip: _____

Work #: _____

Email: _____

- ❑ Crohn's patient
- ❑ Colitis patient
- ❑ My child has Crohn's
- ❑ My child has colitis
- ❑ Other_____

METHOD OF PAYMENT

- ❑ Check enclosed (Please make your check payable to CCFA)
- ❑ Credit card (Please include the following information):
- ❑ Visa/Mastercard ❑ American Express
- ❑ Discover

Account #: _____

Expiration Date: _____

Signature: _____

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