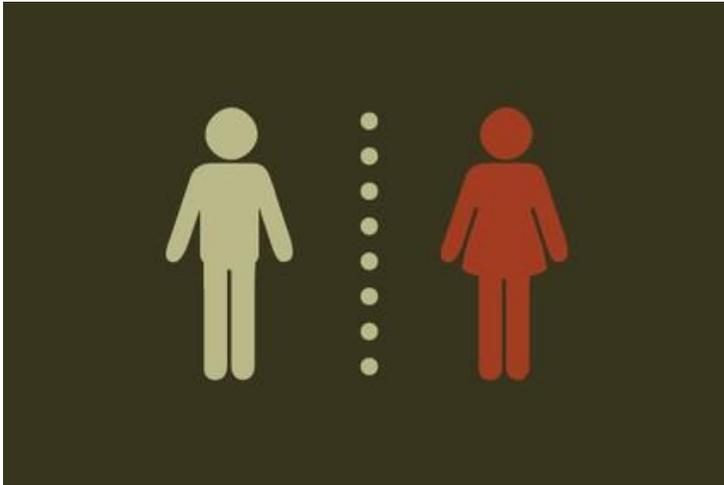


The Grassroots Movement to Change the Nation's Public Restroom Laws

With the rise of inflammatory bowel diseases like Crohn's and ulcerative colitis, some are rethinking how we approach restroom access

By SIMON OWENS

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When Lisa Bain first noticed the look of pain and horror on her daughter Ally's face, she didn't need to ask her what was the matter. The two were shopping in an Old Navy outside of Chicago, and Ally, then 14, had suffered from Crohn's disease for nearly three years.

Few people will ever understand the fear and anxiety someone with Crohn's feels at the thought of appearing in a public place while in the throes of a flare up. An immune disorder, Crohn's (and similar diseases like ulcerative colitis) is characterized by inflammation of the gastrointestinal tract, resulting in diarrhea, abdominal pain, and bleeding.

While in the midst of a flare up, a person with IBD may have to use the bathroom upwards of 30 times a day. As the gastrointestinal tract becomes more inflamed, he or she is unable to control the bowels for more than a few minutes at most. In some cases, it can be less than 60 seconds.

"Most people who have inflammatory bowel disease can always point to where the restrooms are," says Ally, now 22. "They know which restrooms are nice ones, even though when you have to use one you don't even care anymore what the facilities are like. A lot of people can map out exactly where those restrooms are within seconds after arriving somewhere. Many times people won't go somewhere unless they know where the restrooms are located ahead of time."

So after the sharp pains began needling Ally's abdomen, both she and her mother knew she had mere moments to get to the bathroom. Lisa quickly tracked down a fitting room employee and asked him where the customer restrooms were, to which he replied with a phrase every IBD sufferer dreads: "no public restroom."

Hearing those three words brought Ally from a state of anxiety to one of outright panic. As anyone who has IBD knows, the near-constant fear of humiliation is perhaps the worst aspect of the disease, worse even than the physical symptoms. For a girl like Ally, who was two months shy of starting her freshman year of high school, the idea of a life full of such humiliations was terrifying.

"I was at that point in my life when a lot of people are trying to figure out who they are, and yet I'm still battling with whether I can get to the restroom in time," Ally recalls. "So it really makes you challenge that self identity concept because I felt so helpless."

Lisa, not ready to give up without a fight, asked the employee to flag down his manager. Ally, by now hunched over in pain, watched with welling tears in her eyes as the manager walked slowly over to them. When he arrived, Lisa explained her daughter had Crohn's and needed to use the employee restroom. After claiming he knew what the disease was, he said Ally wouldn't be permitted to use the store restroom -- he was making a "managerial decision." He then suggested they cross a four-lane highway to use a restroom in another store.

Within moments, Ally lost what little control of her bowels she had and soiled herself.

"It's still very scarring," she says. "For so long I fought for it not to define me or beat me, and then at that moment I felt like it had."

Lisa was seething in anger. When they returned to their car, she made a solemn promise to Ally: this would never happen to her or anyone else again.

Though that store manager may never know it, by denying Ally use of the bathroom he triggered a chain of events leading to a nationwide movement aimed at reforming state bathroom policies. In the eight years since, 13 states have passed laws forcing businesses to offer access to restrooms for those suffering from both bowel and bladder control problems. Many refer to it by the same name: Ally's Law

Why has support for these reforms suddenly exploded? Dr. James Lewis, a professor of medicine and clinical epidemiology at the University of Pennsylvania, says the rise of autoimmune diseases has reached "epidemic" proportions.

"It's estimated that 1.4 million Americans have IBD," he says in a phone interview. "If you expand that to all autoimmune diseases, it gets up to about 23.5 million Americans, or about one in 12. When you think about that, you realize this is becoming such an enormous public health issue."

With each autoimmune disease -- whether it's lupus, rheumatoid arthritis, Type 1 diabetes, or IBD -- the body is in a state of war with itself, the immune system attacking what it considers enemy tissues. For those with ulcerative colitis, for example, the colon begins to develop ulcers that then start to bleed. Left untreated, it can lead to hospitalization and emergency blood transfusions. In most cases, the only treatment for such a disorder is to suppress the immune system with the help of steroids until it goes into remission. In recent years, there is increasing use of alternatives to steroids, including some medications that were initially used to treat cancers or prevent organ transplantation. Many of these medications bring unwanted side effects and risks of infection.

There are a number of theories as to why there has been such a sudden spike of these diseases. One that's been gaining momentum of late is often referred to as the Hygiene hypothesis.

"It's the idea that we're just too clean," Lewis explains. "We're exposed to too many antibiotics, and a lot of these may link back to some fundamental biology relating to what's going on with the microorganisms living in our intestines today compared to centuries ago."

Scientists who subscribe to this idea believe we evolved along with thousands of species of microbes, and the rise of antibiotics, while beneficial for treating once-deadly infections, has eliminated many of the microorganisms that helped regulate our immune system.

As evidence to support this hypothesis, they point out that autoimmune disorders predominantly exist in Western countries with more access to modern medicine and clean water.

Scientists have also found both genetic and environmental factors at play. And as they continue searching for a cure, doctors have become much better at diagnosing these diseases. With increased awareness, IBD became less stigmatized, allowing more people to speak out on it.

"I think historically, we just don't talk about our bowel patterns in public," Lewis says. "But this is one of lots of things becoming destigmatized. There were lots of diseases that people were uncomfortable talking about 20 years ago, and today I think our society is becoming a little more accepting of the reality that people have diseases to deal with, but it doesn't mean they can't be active or important members of society."

In fact, if you trace the trajectory of Ally's Law from state to state, its most vocal proponents were those who either suffered from IBD or knew someone who did. In Massachusetts, the state that most recently passed such a law, Boston mayor Thomas Menino, a longtime Crohn's sufferer, was one of its most outspoken supporters. In the last decade a number of celebrities, including Mike McCready, the lead guitarist of Pearl Jam, have come out and discussed their IBD with the public.

For a law that had never been enacted in another state, Ally's Law moved fairly swiftly through the Illinois legislature. Bain was aided, in part, by then-State Rep. Kathy Ryg, her state legislator she'd met only a few months before during an eighth grade field trip. After explaining briefly how a bill becomes a law, Ryg handed the students a directory listing of all the state legislators.

"I remember my classmates not really caring, just flipping through it," Bain says. "But I was just in awe, standing in that rotunda just outside the House floor. I didn't quite understand what they did fully, but I got the idea that these lawmakers can make a difference and that we could have some say in it."

After the store incident, Bain pulled out the directory she'd been given and left a message with Ryg's office.

Ryg, who retired from the House in 2009, still remembers that call and the subsequent visit from Bain and her mother to her office. "They gave me the background of the story," she recalls. "It is one of those not uncommon things I've experienced where common sense would have dictated that she should have been allowed to use the restroom and that would have been the end of it."

But based on my personal experience, the managers in these stores are often young people and they follow store policy and don't always have the ability to make a judgement call."

Ryg, who was in her freshman year as a state representative, embarked on a journey to address this issue with a law, first by determining whether other states had passed such legislation. When it became clear that it would be, for the most part, unprecedented, her office began researching which components would need to come together for such law to become practical, including "who we needed to get input from in terms of making it something that wasn't just a law on the books but a law that could be implemented."

Within nine months, Bain found herself testifying before a House judiciary committee, retelling the story of that dreadful day. Standing in opposition to the bill, not only in Illinois but in several subsequent states, were groups representing both the retail and petroleum industries.

"I can't say that we 100% opposed it," says Jon Hurst, president of the Retailers Association of Massachusetts, of the law's passage in his state. "We were concerned why we were being singled out, why the retail sector was being singled out." He points to a number of state government buildings and other types of businesses that weren't targeted by the legislation.

He says they also had concerns about liability, as well as theft.

"Maybe the route to the bathroom goes through the storage room where you're storing a lot of your goods and you happen to be a type of establishment where you have a real shoplifting and theft problem."

The petroleum industry had a similar complaint: It argued that if a station employee were to escort a customer to a bathroom, it would become a security and safety issue, potentially allowing someone to steal from the store.

Because of this opposition, Illinois and other states have carved out exemptions for retail businesses with fewer than three employees, as well as for gas kiosks. Many states have also placed in language protecting businesses from lawsuits for any accidents that may occur in their restrooms.

Once Illinois passed the law, the floodgates opened. Before she knew it, Ally was contacted by other sufferers across the country via E-Mail, Facebook and Twitter to help them lobby their own representatives. National organizations like the Crohn's and Colitis Foundation of America became involved, and it snowballed from there.

Not everyone is on board with Ally's Law, however, including at least one surprising activist.

Robert Brubaker, a program manager for the American Restroom Association, an advocacy group formed in the 2005 to increase quality and access to restrooms, doesn't like it when there are exemptions carved out for IBD sufferers to use restrooms.

Why?

"Because it makes it sound like you don't already have the privilege," he says.

To understand Brubaker's opposition to laws like this one, one must first consider whether access to a toilet is a basic human right, a right grounded in one simple truth: as animals, we all, at some point, need to dispel our waste, and some of us may not always be able to wait very long.

Though many versions of Ally's Law are written to include all conditions affecting the bladder and bowels, he believes it sends a message to retailers that they can ignore the needs of those who fit outside these narrow categories.

"Let's fix it for everybody, even for the healthy person who got food poisoning. They don't normally have a problem but they do today," he says.

What perplexes Brubaker is that there are already laws in existence addressing issue, including many state-based building codes, and he argues IBD activists should focus simply on getting them enforced.

Nearly a decade has passed since the horrific incident that propelled Ally Bain into the spotlight and down a long road of activism. That day she had been awash with humiliation, anger, and worry for how a life with this disease would affect her. Would she forever be defined by this disease, unable to look past the debilitating symptoms and afraid to venture out of the house?

"I would say that one incident showed me the importance of turning a negative situation into a positive outcome," she says. "Speaking out about an illness that is so often stigmatized because of the symptoms associated with it has allowed me to show that I've overcome the disease."

Ally graduated from Chicago's Lake Forest College in May. She's now working at the Center for the Constitution at James Madison's Montpelier in Virginia, but has law school in her sights, a sign her life of activism may only just be beginning.

Perhaps the store incident had shaped the trajectory of her life, just not the way her 14-year-old self thought it would.

"I haven't let [IBD] define me," she reflects. "But I also use it as a platform to help other people who are not able to use their voice."

http://www.usnews.com/news/articles/2012/12/20/the-grassroots-movement-to-change-the-nations-public-restroom-laws_print.html

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