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## Inflammatory Bowel Disease and Advocacy

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### Crohn's & Colitis Foundation

**Advocacy** supports the Foundation's mission:

*To cure Crohn's disease and ulcerative colitis, and to improve the quality of life of children and adults affected by these diseases.*




### What is inflammatory bowel disease?

- Crohn's disease and ulcerative colitis are both major categories of inflammatory bowel diseases (IBD).
- Crohn's disease is a chronic inflammatory condition of the gastrointestinal tract and may affect any part from the mouth to the anus.
- Ulcerative colitis is a chronic inflammatory condition limited to the colon, otherwise known as the large intestine.
- Collectively, IBD affects an estimated 3.1 million Americans.

Commonly shared symptoms:

- Diarrhea
- Rectal bleeding
- Urgent need to move bowels
- Loss of normal menstrual cycle
- Abdominal cramps and pain
- Constipation
- Fever
- Loss of appetite
- Weight loss
- Fatigue
- Night sweats



### What We Do

*We advocate with patients and providers to address state and federal policies related to access to care and medical research.*

**Federal Advocacy –**

- Medical research funding
- Access to care legislation
- Agency regulations

**State Advocacy –**

- **Key states:** CA, GA, MA, MI, OH, WA, and MN




### Foundation Priorities



Step therapy

Cost of care





### Step Therapy – The Issue

Have you been required by your health insurer to try and fail on a medication before coverage was provided for your original provider-prescribed treatment?

If so, you've been subjected to step therapy, also known as "fail first."




### Step Therapy Reform Legislation

Bill summary:

- Requires health plans to implement a clear appeals process
- Establishes a 24-72 hour time frame in which insurers must respond to appeals
- Establishes circumstances in which a patient may be exempt from step therapy when medically appropriate

#### IBD Patients and Step Therapy Protocol

In a survey of 2,600 IBD patients:

- 40%** indicated they had been subject to step therapy
- 59%** were delayed from their optimal treatment plan for over three months

Of those:

- 58%** of patients were required to fall two or more drugs before having access to the originally prescribed drug
- 3%** were delayed for over seven months
- 60%** were unable to have a doctor intervene to stop the step therapy process on their behalf
- 94%** believe step therapy to be a barrier to timely and appropriate care

\*National survey performed by the Crohn's & Colitis Foundation. 2,600 respondents were surveyed in December 2018.

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### Step Therapy Reform in the States

Legend: ● Patient protections enacted ● Targeted ● Silent

Legislation needs to be passed in all states and in Congress to cover both state (i.e. marketplace, state employee, and fully-insured) and federally-regulated (i.e., ERISA, and self-insured) health plans.

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### Cost of IBD

IBD patients have **twice** the out-of-pocket costs than non-IBD patients.

\* per-year reported out-of-pocket costs

IBD PATIENT

**\$2,213\***

NON-IBD PATIENT

**\$979\***

IBD patients are estimated to have **3 times more** work-related lost wages than non-IBD patients.

\* estimated using the median wage in the US

IBD PATIENT

**\$3,000\***

NON-IBD PATIENT

**\$1,000\***

Children with IBD and IBD patients older than 65 have up to **46% higher** cost burden.

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### Cost of IBD – Cont.

- The Foundation supports policies which limit the maximum out-of-pocket expenses for individuals
- Cost is the greatest barrier to quality care for IBD patients
- High costs decrease utilization of necessary medications
- Key drivers of cost include:
  - Emergency dept. use
  - Healthcare service utilization associated with anemia or mental health condition
  - Treatment with specific therapeutics

Healthcare costs for IBD patients are more than **3 times** that of non-IBD patients.

\* per-member per-year paid claims

IBD PATIENT

**\$22,987\***

NON-IBD PATIENT

**\$6,956\***

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### Thank you!

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