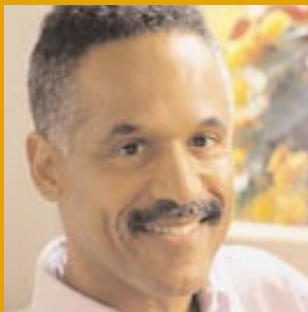


# IBS in the Real World Survey

SUMMARY FINDINGS **AUGUST 2002**

International Foundation for Functional Gastrointestinal Disorders







## The International Foundation for Functional Gastrointestinal Disorders

(IFFGD) sponsored a quantitative research study among U.S. adults from their international patient database. All respondents (n=350) reported having an Irritable Bowel Syndrome (IBS) diagnosis and participated in a telephone survey. Fieldwork took place from February 6–March 2, 2002.

# Dear reader,

IFFGD was founded in 1991 in response to a lack of awareness, understanding and treatment options for people suffering with Irritable Bowel Syndrome (IBS), fecal incontinence and other gastrointestinal disorders.

From simple beginnings more than a decade ago, our organization has grown to one with international reach and profound impact on the lives of millions. Our steadfast commitment to credible, unbiased education and advocacy for patients has attracted the attention of clinicians, the Food and Drug Administration, Congressional leaders and other decision-makers who affect the treatment options of patients.

Over the years, thousands of people have contacted us for information, assistance and support in finding effective treatment for gastrointestinal (GI) disorders. From their telephone calls, mail inquiries and Web visits, we have developed an international database of people suffering with GI disorders. For this survey, we contacted a random sample from our database of U.S. adults diagnosed with IBS and conducted telephone interviews. The response was extraordinary; people generously gave of their time and willingly answered questions about their disease, symptoms, treatment, side effects and the overall impact IBS has on their lives.

We recognize that the information we received in this random survey may reflect a subset of sufferers with IBS who are particularly troubled or more disabled by their symptoms than others with IBS. This group may be more likely to choose to share their experiences through a survey. Therefore, we cannot generalize our results to a possibly larger proportion of persons with IBS who have milder symptoms or have developed effective coping strategies. Nevertheless, the information from these respondents speaks for itself in communicating the tremendous burden IBS can impose upon a large proportion of sufferers.

We invite you to read the fascinating details in this summary report. As patient advocates, we have often thought that the severity, frequency and pain associated with IBS symptoms are underestimated, making it difficult for the treatment needs of this chronic disease to be fairly evaluated. The findings of our study confirm these concerns. For example, our survey shows that 43% of respondents reported their symptoms as severe, 47% reported daily episodes of IBS and more than one third (39%) rated the pain of their IBS symptoms as extreme or very severe.

We were also struck by the extent of missed work and leisure activities endured by these respondents due to IBS. Interestingly, leisure activities were foregone much more than work, leading us to believe that these people are sacrificing huge parts of their personal lives as they battle their symptoms. These findings paint a distressing portrait of the disease and one that deserves intensified research attention to identify safe, effective treatments.

We are pleased to share these research results with you and sincerely hope that they help in your quest for a more complete understanding of IBS and the people who suffer from it.

Sincerely,



**Nancy J. Norton**  
*President and Founder*  
International Foundation for  
Functional Gastrointestinal Disorders



**Douglas A. Drossman, MD**  
*IFFGD Board Member*  
*Co-director of the UNC Center for*  
Functional GI & Motility Disorders  
*Professor of Medicine and Psychiatry*  
University of North Carolina



# IBS: THE DISEASE

## ■ Research participants reported living with IBS for years.

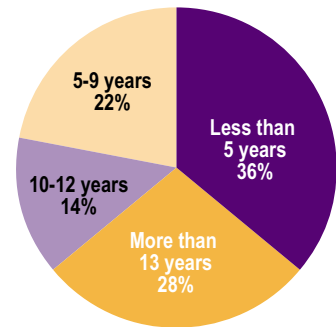
Almost half of this sample (42%) reported being diagnosed with IBS ten or more years ago, and almost two-thirds have lived with IBS for five or more years.

## ■ Sufferers face the challenge of their disease day in and day out.

71% of this sample reported two or more episodes per week. Nearly half (47%) of IBS sufferers reported daily episodes of IBS symptoms.

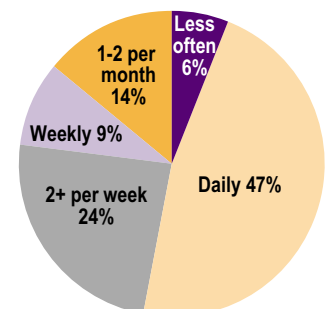
■ 56% of male sufferers and 43% of female sufferers report daily episodes.

Years Living With IBS



Base = 340 who could recall

Frequency Of IBS Episodes



Base = 345





Ongoing or continuous durations of IBS episodes were reported by one-quarter of respondents.

#### Length Of A Typical IBS Episode, Beginning To End

|                                     | Predominant Symptom |          |       |              |
|-------------------------------------|---------------------|----------|-------|--------------|
|                                     | Total               | Diarrhea | Mixed | Constipation |
| Less than one day                   | 40%                 | 48%      | 43%   | 21%          |
| 1 – 2 days                          | 16                  | 14       | 23    | 13           |
| More than 2 days, less than a week  | 8                   | 8        | 8     | 10           |
| More than 1 week, less than 2 weeks | 2                   | 1        | 1     | 3            |
| 2 weeks to 1 month                  | 3                   | 1        | 2     | 7            |
| Month or more, not continuous       | 3                   | 2        | 3     | 6            |
| Ongoing/continuous/every day        | 24                  | 22       | 18    | 34           |
| Varies, depends on diet/medication  | 1                   | 2        | 1     | 1            |
| Don't know/No answer                | 3                   | 2        | 1     | 5            |
| (Base)                              | (350)               | (171)    | ( 93) | ( 86)        |

#### Diarrhea was reported as the predominant condition.

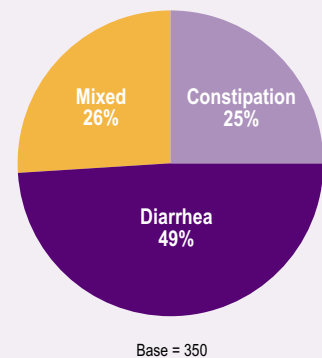
Diarrhea, either alone or in combination with constipation, was cited as the predominant IBS condition by three-quarters of sufferers.

Although diarrhea was cited as the predominant condition by both men and women, more female sufferers (27%) cited constipation as their predominant condition as compared to male sufferers (17%).

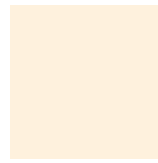
#### Predominant Condition By Gender

| Gender | Diarrhea | Mixed | Constipation | (Base) |
|--------|----------|-------|--------------|--------|
| Male   | 51%      | 32%   | 17%          | ( 75)  |
| Female | 48%      | 25%   | 27%          | (275)  |

#### Predominant Condition

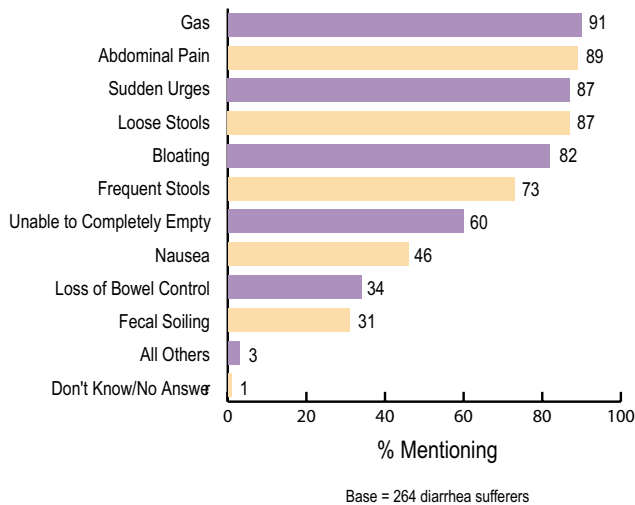






# IBS: SYMPTOMS

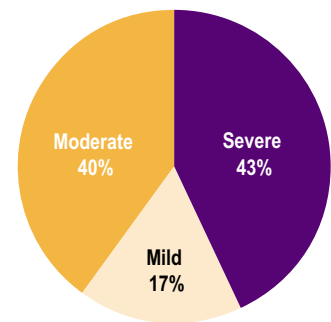
## Symptoms Ever Experienced — Diarrhea Sufferers



■ Respondents reported suffering from severe and painful symptoms.

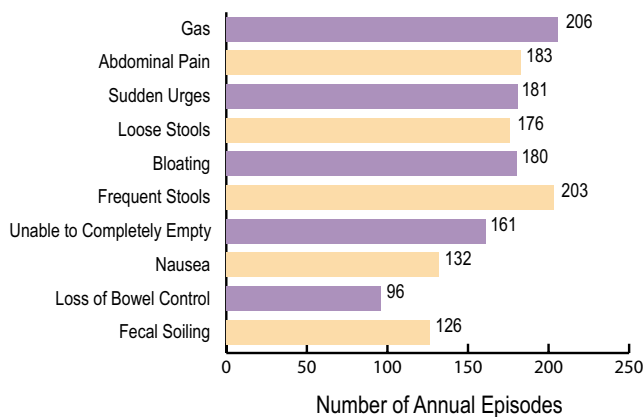
Slightly under half (43%) reported symptoms as “severe.” 40% described symptoms as “moderate” and less than one-fifth reported symptoms as being “mild.”

## Self-described Severity Of Symptoms



More than one third (39%) rated the *pain* of their IBS symptoms as extreme or very severe.

## Mean Episodes Per Year For Diarrhea Sufferers



■ Multiple symptoms were reported by diarrhea sufferers.

Gas, abdominal pain, sudden urges and loose stools were cited by approximately nine of ten respondents. More than one third (34%) of diarrhea sufferers experienced loss of bowel control.

■ When asked about their *most bothersome* IBS symptoms, 43% of diarrhea sufferers identified abdominal pain or discomfort, while 37% reported sudden urges to have bowel movements.

On an average basis, the frequency of symptoms reported by diarrhea sufferers translates to over 200 episodes a year for gas and frequent stools.



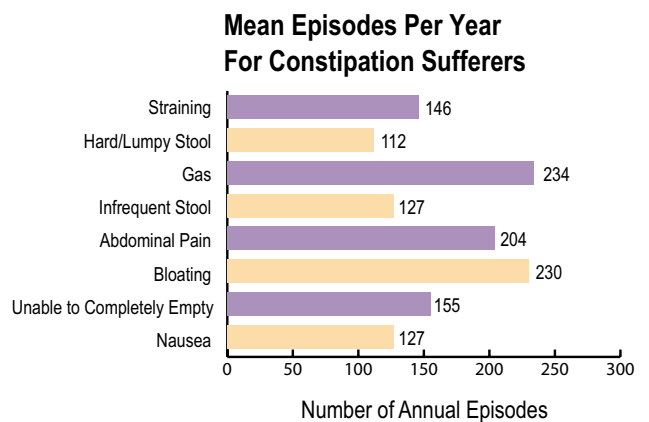
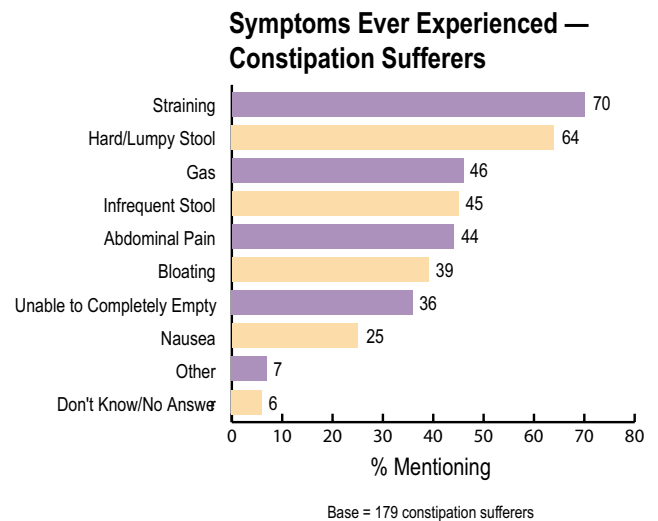


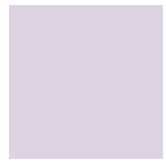
## ■ Constipation-specific symptoms were varied and frequent.

Among respondents who suffer from constipation, straining when having a bowel movement and hard or lumpy stools were the symptoms most often reported.

■ Approximately one-quarter of constipation sufferers reported abdominal pain, straining, infrequent stools, bloating and/or gas when asked about their *most bothersome* symptoms.

Episodes of gas, bloating and abdominal pain were each described by constipation sufferers as occurring with an average frequency of over 200 times a year.





# IBS: LIFESTYLE IMPACT

■ IBS symptoms were described as seriously impacting daily life, causing frequent absences from work and school.

IBS symptoms were described as extremely or very bothersome by two-thirds of sufferers, in terms of interfering with daily comfort, work or activities with friends or family.

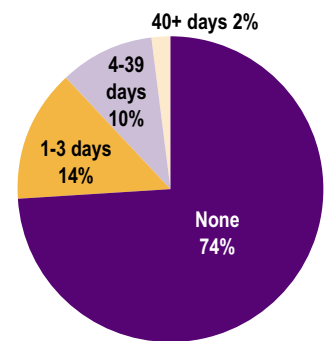
5% of respondents reported being on disability due to their IBS.



Missing work or school due to IBS symptoms in the past three months was reported by more than one-quarter of survey respondents (26%).

■ Of those who reported missing work, nearly one in thirteen reported daily episodes, not being able to work or having to move their business into their home.

Days Of Work/School Missed, Prior 3 Months

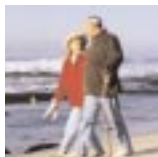


Base = 345

Among those citing work/school absences, an average of almost eight missed days in a three-month period was reported (more than once every other week). Men reported work absences more frequently than women.

Missed Work/School, Prior 3 Months

|        |        | Did Not Miss Work | Missed Work | Average Days Missed | (Base) |
|--------|--------|-------------------|-------------|---------------------|--------|
| Total  |        | 74%               | 26%         | 7.9                 | (345)  |
| Gender | Male   | 71%               | 29%         | 12.3                | ( 73)  |
|        | Female | 74%               | 26%         | 6.6                 | (272)  |



## ■ IBS sufferers have to arrive late or leave early from work or school due to their disease.

The need to either arrive late for work or school or to leave early due to an IBS episode was reported by more than one-quarter of respondents.

Of those who reported arriving late or leaving early, more than one respondent in ten reported more than 30 such incidents in a three-month period.

## ■ IBS symptoms caused missed leisure activities even more than absenteeism at work or school.

Missed leisure activities were reported as occurring among just over two-thirds of these respondents (68%).

- 5% reported missing such occasions more than 50 times in the three-month period.

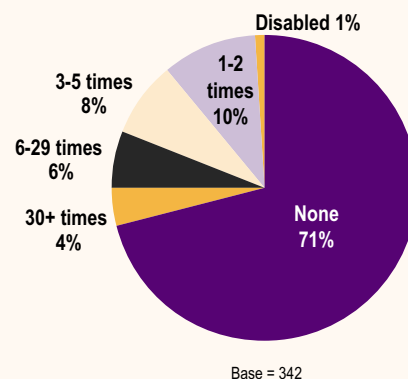
Those who reported missing leisure activities reported an average of 11 missed activities/occasions in the three-month period, or almost one per week.

Missed leisure activities were reported more frequently by those who described their IBS symptoms as severe and men reported missing activities directionally more often than women.

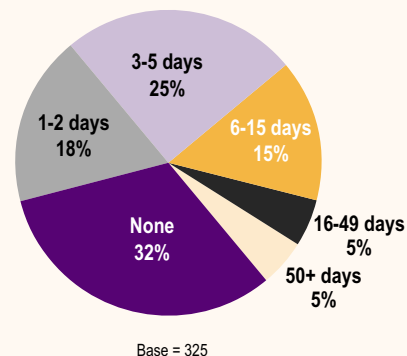
### Missed Leisure Activities, Prior 3 Months

|                 |                      | Did Not Miss | Missed Activity | Average Days Missed | (Base) |
|-----------------|----------------------|--------------|-----------------|---------------------|--------|
| <b>Total</b>    |                      | 32%          | 68%             | 10.5                | (325)  |
| <b>Symptoms</b> | <b>Severe</b>        | 19%          | 81%             | 15.9                | (129)  |
|                 | <b>Moderate/Mild</b> | 40%          | 60%             | 5.6                 | (192)  |
| <b>Gender</b>   | <b>Male</b>          | 39%          | 61%             | 12.3                | ( 67)  |
|                 | <b>Female</b>        | 30%          | 70%             | 10.0                | (258)  |

### Leave Early From Or Arrive Late To Work/School, Prior 3 Months

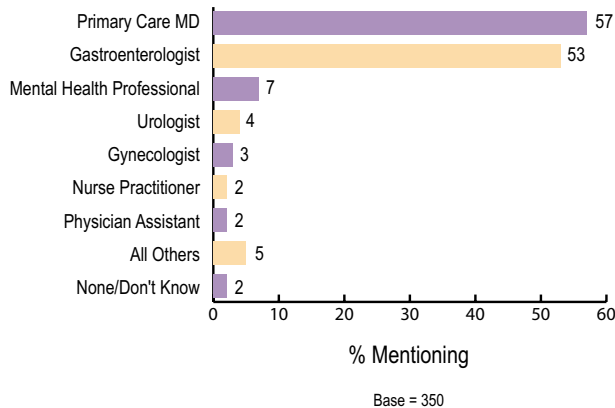


### Days Of Leisure Missed, Prior 3 Months





**Health Care Provider Most Frequently Seen For IBS**



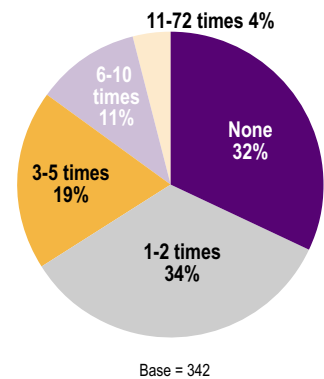
# IBS: HEALTH CARE PROVIDERS

■ IBS sufferers seek care from primary care physicians and gastroenterologists.

While many reported multiple sources of care, just over half (57%) reported a primary care physician as most frequently seen for IBS treatment, followed closely by gastrointestinal specialists (53%).

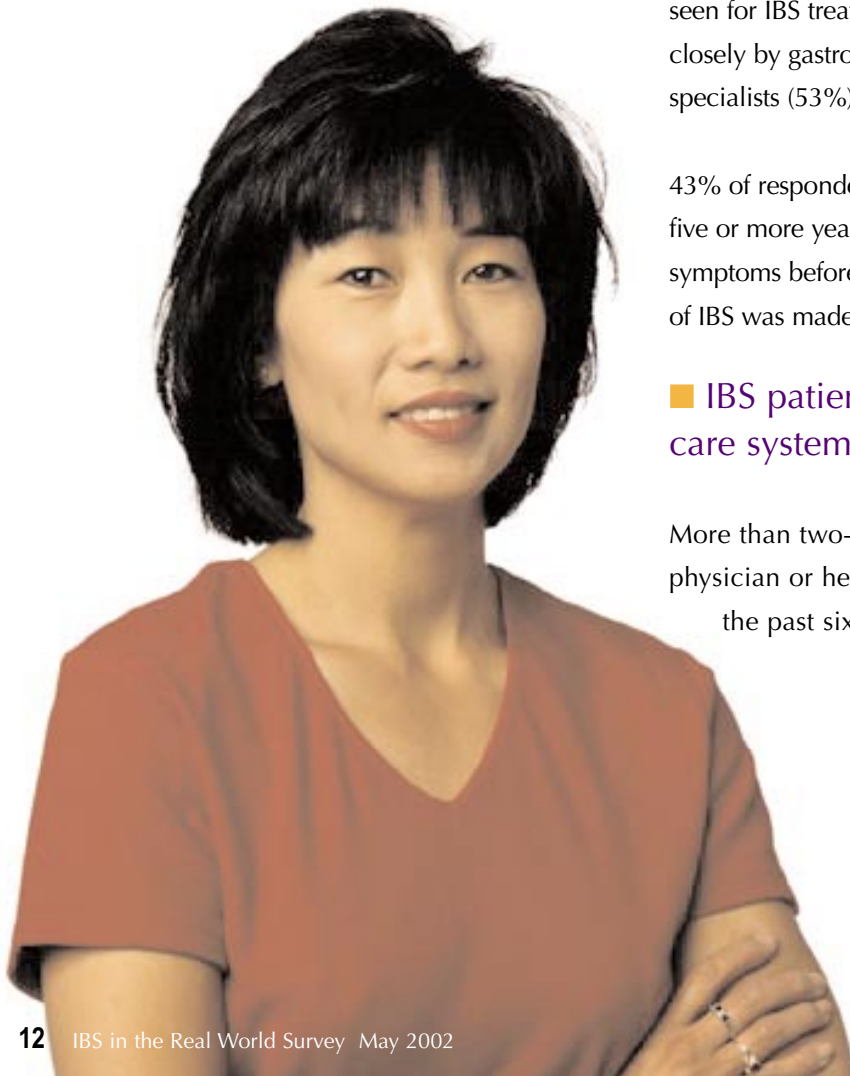
43% of respondents suffered five or more years with symptoms before a diagnosis of IBS was made.

**Health Care Provider Visits, Prior 6 Months**



■ IBS patients are heavy users of the health care system.

More than two-thirds reported visiting a physician or health care provider during the past six months for their IBS.





A full 15% of the total sample reported six or more visits, with 4% reporting 11-72 visits.

Both men and women report multiple visits to their health care providers for their IBS.

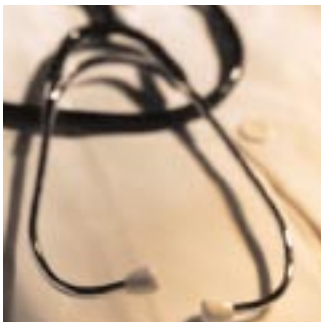
#### Gender Split

|                                | Male  | Female |
|--------------------------------|-------|--------|
| Daily episode of IBS           | 56%   | 43%    |
| Provider visits, last 6 months | 64%   | 70%    |
| Mean visits, last 6 months     | 3.5   | 4.5    |
| (Base)                         | ( 75) | (275)  |

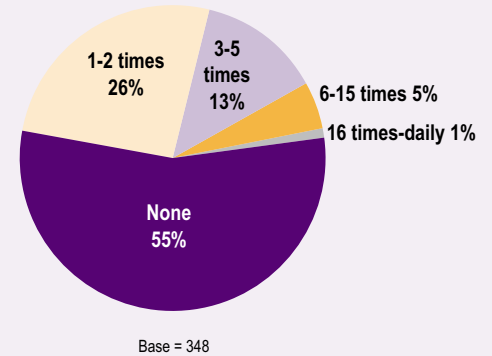
Nearly half (45%) reported calling a physician or health care provider about their IBS symptoms during the past three months.

- Of those who did call, the average number of calls reported was 4 calls in three months, or one provider call every three weeks.

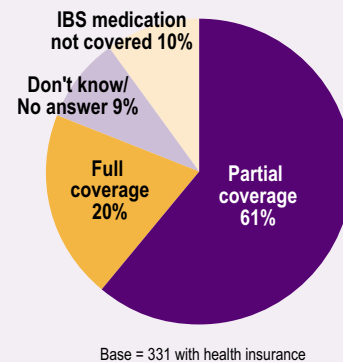
More than three-quarters of respondents reported insurance coverage for at least a portion of the cost of IBS medications.

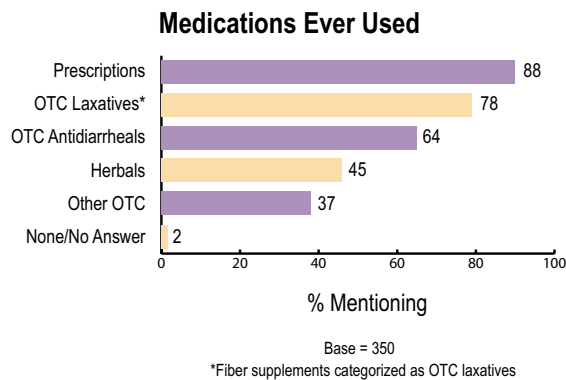


#### Provider Calls, Prior 3 Months

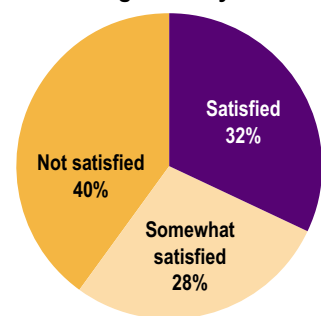


#### IBS Medication Covered By Health Insurance





### Overall Drug/Remedy Satisfaction



Base = 315 who currently take prescription medications, OTC medications or herbal/nutritional supplements

# IBS: TREATMENT

■ Hundreds of treatments are used by these IBS sufferers.

Respondents reported using 281 different treatments — including prescription drugs, over-the-counter (OTC) medications and herbal and dietary supplements — to control their symptoms.

- A full 88% of this sample reported using prescription drugs to treat IBS symptoms.
- 78% reported use of OTC laxatives and almost two-thirds (64%) reported use of OTC anti-diarrheals.
- Use of herbal remedies was cited by 45% of respondents.

■ Research participants are dissatisfied with their medications.

Fewer than one-third of these IBS sufferers reported satisfaction with the drugs and remedies they currently use to treat their IBS symptoms.

■ Respondents rate effectiveness of prescription drugs.

Less than half (45%) of respondents described the prescription drugs they currently use as “effective.”

- Prescription medications were rated as “not effective” by 22% of those who currently take them and 33% describe prescription drugs as only “somewhat effective” in treating IBS symptoms.



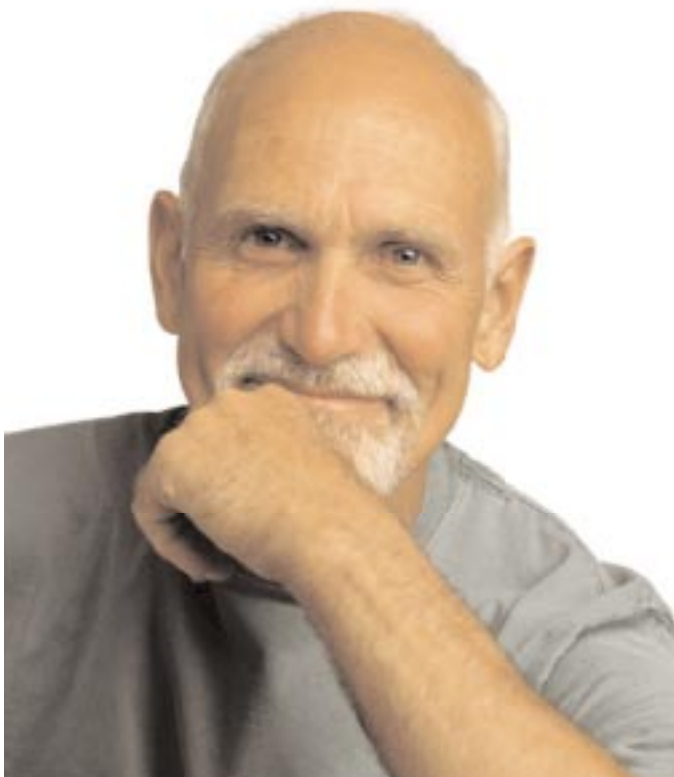


■ Respondents rate effectiveness of OTC medications even lower than prescription drugs.

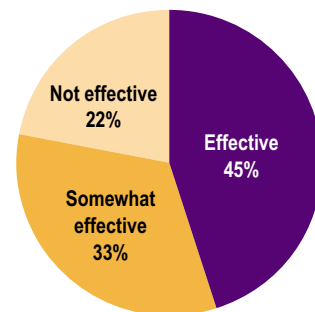
OTC medications were rated as “not effective” by 40% of those who currently take them. As with prescription drugs, only 33% describe OTC medications as “somewhat effective” in treating IBS symptoms.

■ Respondents also report low effectiveness ratings for herbals and nutritional supplements.

As with OTC medications, 40% of those who reported using herbals or nutritional supplements assigned ratings of “not effective” and only 31% thought they were “somewhat effective.”

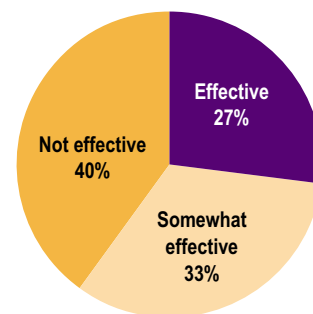


### Prescription Drug Effectiveness



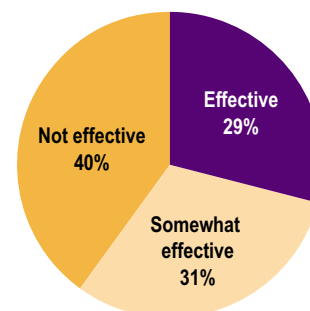
Base = 217 who currently take prescription medications

### OTC Medication Effectiveness



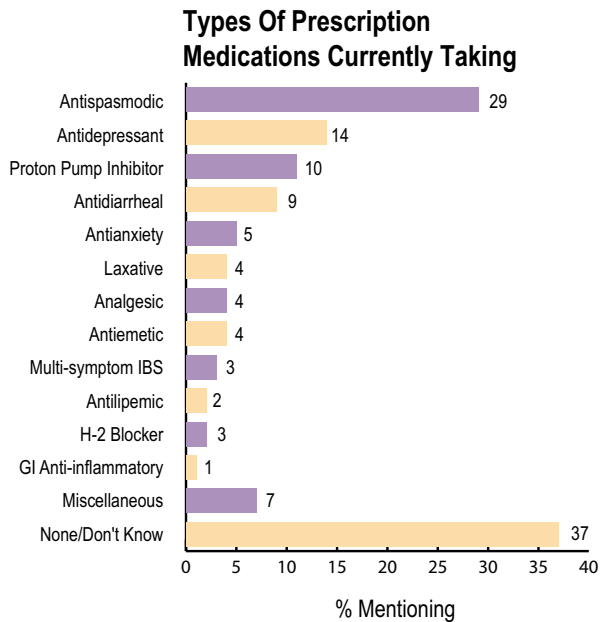
Base = 256 who currently take OTC medications

### Herbal/Nutritional Supplement Effectiveness



Base = 90 who currently take herbal/nutritional supplements





Note: An unusually large segment (37%) fell into None/Don't Know because many of these respondents could not name the class or brand of prescription drugs taken.

# IBS: CLOSE-UP ON RX DRUGS

■ Respondents reported using multiple classes of prescription drugs for IBS symptoms.

No single class of prescription drugs was mentioned as being used by as many as one-third of respondents.

■ Of all the prescription types, antispasmodics were mentioned most often — more than twice as often as any other kind of prescription drug.

■ IBS sufferers provide mixed feedback on prescription drugs.

The most frequently cited reasons for dissatisfaction dealt with perceptions of efficacy; 89% of mentions of dissatisfaction related to:

- Lack of effectiveness
- Symptoms not relieved
- Pain and discomfort
- Bathroom habits unrelieved

Prescription drugs were more often considered to be effective by those whose condition is diarrhea-predominant.

■ Among this segment, half (50%) assigned the highest two ratings of satisfaction with prescription effectiveness, in contrast to only 35% of those whose condition is constipation-predominant.





Prescription drugs were more often considered to be effective by those who either have better controlled symptoms or milder cases of IBS. Higher ratings of satisfaction with the effectiveness of prescription drugs occurred most often among:

- Those describing symptoms as moderate/mild (50%).
- Those describing the frequency of episodes as less than weekly (51%).
- Those describing symptoms as not interfering with daily activity (63%).

#### Effectiveness Rating Of Prescription Medication

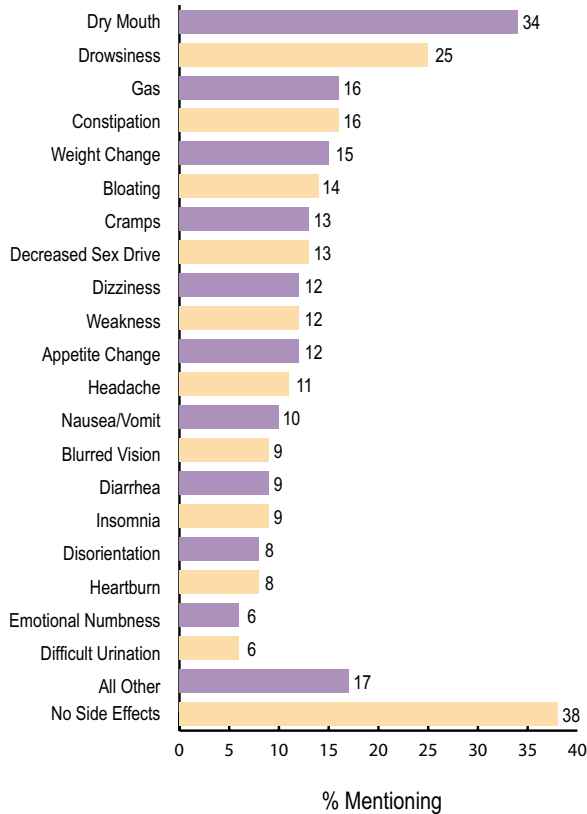
|              |                  | Effective | Somewhat | Not Effective | (Base) |
|--------------|------------------|-----------|----------|---------------|--------|
| Condition    | Diarrhea         | 49%       | 32%      | 17%           | (107)  |
|              | Both             | 43%       | 36%      | 19%           | (58)   |
|              | Constipation     | 34%       | 31%      | 34%           | (55)   |
| Symptoms     | Severe           | 37%       | 34%      | 26%           | (99)   |
|              | Moderate/mild    | 50%       | 30%      | 19%           | (118)  |
| Frequency    | Daily            | 42%       | 33%      | 24%           | (106)  |
|              | Weekly           | 45%       | 30%      | 24%           | (71)   |
|              | Less than weekly | 51%       | 37%      | 12%           | (41)   |
| Interference | Bothersome       | 37%       | 36%      | 25%           | (161)  |
|              | Not              | 63%       | 24%      | 13%           | (59)   |

Note: Rows do not always equal 100% due to Don't Know/No Answer responses.



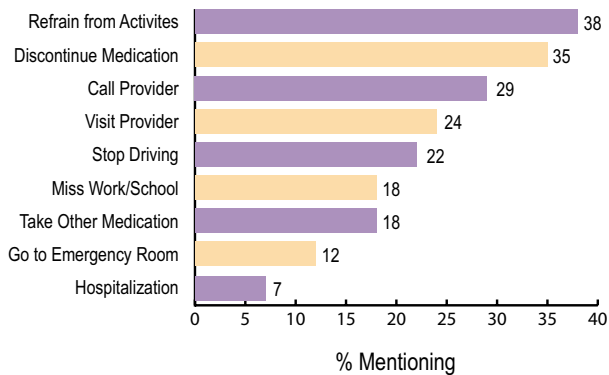


### Current Prescription Side Effects



Base = 220 currently taking prescription drugs

### Results Of Prescription Side Effects



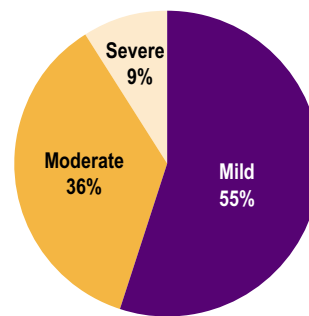
Base = 136 with side effects

# IBS: SIDE EFFECTS

■ Side effects of prescription drugs distress IBS sufferers.

Of those taking prescription drugs, 62% report side effects. Almost half (45%) reported the side effects as severe or moderate.

### Side Effects Of Prescription Medication

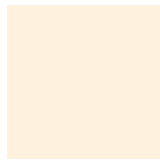


Base = 136 with side effects

The most frequently cited side effects of current prescription drugs were dry mouth (mentioned by a full one-third of those currently using prescription drugs) and drowsiness (mentioned by one-quarter).

Those respondents reporting side effects also reported adverse events.

- 12% had to visit an ER.
- 7% were hospitalized.
- 29% had to call their health care provider and 24% had to visit their health care provider.
- 22% had to stop driving.
- 18% reported missing work or school.



## ■ Profile of the national study's sample

While all 350 (100%) respondents had been diagnosed with Irritable Bowel Syndrome, some reported additional diagnoses:

- 14% reported inflammatory bowel disease, Crohn's disease or ulcerative colitis
- 14% reported diverticulosis or diverticulitis
- 3% reported peptic ulcer disease
- 1% reported infectious colitis
- 1% reported cancer

The median age of this sample of IBS sufferers was 51 years.

### Age Groups

| Age        | Percent of Sample |
|------------|-------------------|
| 20 & under | 1%                |
| 20-29      | 5%                |
| 30-39      | 15%               |
| 40-49      | 26%               |
| 50-59      | 25%               |
| 60-69      | 16%               |
| 70-79      | 9%                |
| 80 & above | 3%                |

The sample's gender breakout was 79% female and 21% male.

All respondents resided in the United States, with the following geographic breakout:  
East - 40%; Central - 40%; West - 20%

Other demographics of note include:

- Married (three-quarters)
- No children living at home (three-quarters)
- Educated (nearly seven in ten at least some college)
- Median income \$59,400





## **Our Unique Mission:** The International Foundation

for Functional Gastrointestinal Disorders (IFFGD) is a

nonprofit education and research organization dedicated

to informing, assisting and supporting people affected by

gastrointestinal disorders. The largest organization of its kind in the

U.S., IFFGD has been working since 1991 with patients, families,

physicians, practitioners, researchers, employers, regulators and

others to broaden understanding about gastrointestinal disorders.

**International Foundation  
for Functional  
Gastrointestinal Disorders**

P.O. Box 170864  
Milwaukee, WI 53217  
Toll-free: 888-964-2001  
Business: 414-964-1799  
Fax: 414-964-7176

E-mail: [iffgd@iffgd.org](mailto:iffgd@iffgd.org)  
[www.iffgd.org](http://www.iffgd.org)  
[www.aboutibs.org](http://www.aboutibs.org)  
[www.aboutincontinence.org](http://www.aboutincontinence.org)  
[www.aboutgerd.org](http://www.aboutgerd.org)  
[www.aboutkidsgi.org](http://www.aboutkidsgi.org)