



**MICROSCOPIC COLITIS NEWSLETTER**

**Volume 10, Issue 2  
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## **Survey Results: Part 1 Demographics and Medications**

**by Rosalyn Upson**

First of all, a big “Thank You” to the 1,416 people who filled out the survey. The Foundation has accumulated a lot of information over the years about the disease, and has reported on various treatments. The power of numbers provided by the survey will help us understand much better the course of the disease, and provide insights into how successful various treatments have actually been. You can look at the charts, and see how your particular journey fits into what others have experienced.

This newsletter will focus on the demographics of those who responded to the survey, and look at how patients responded to the more widely used medications. One factor we didn’t take into consideration were the respondents from other countries. The names of the medications can be different, and this caused confusion. Some respondents contacted us about this issue, and future surveys will take this into account.

The next newsletter will look at the results of the survey for diet, and what this tells us about our shared experiences. This will help inform each person's choices about treatment.

### **Demographics**

The pool of survey participants comes from those who subscribe to the newsletter and who visit the Forum, the Foundation website, and several MC Facebook groups, representing a broad

variety of MC patients.

## Gender

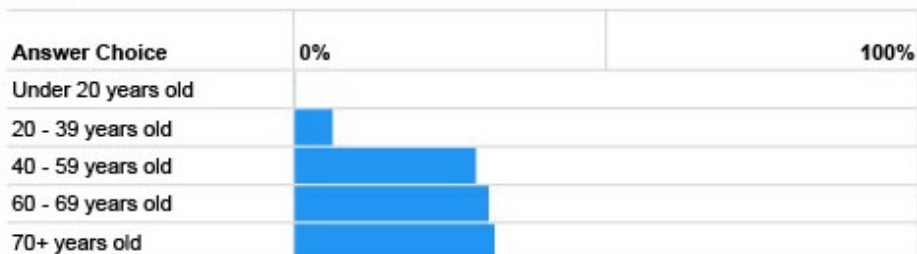
Microscopic colitis affects around two to three as many females as males, according to published data. The survey responders were 92% female, and 6 % male. Women in general are more motivated to respond to surveys, and participate in social media than men. This could explain the high percentage of female respondents.

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## Age

MC has the stereotype of being primarily a disease of older women, but we know from over 10 years of Forum reporting that it can affect any age group or gender. As you can see from the data, it does skew toward the older age groups. But 35% are under 60 years old, and doctors should be aware of the possibility of MC in younger age groups with chronic diarrhea.

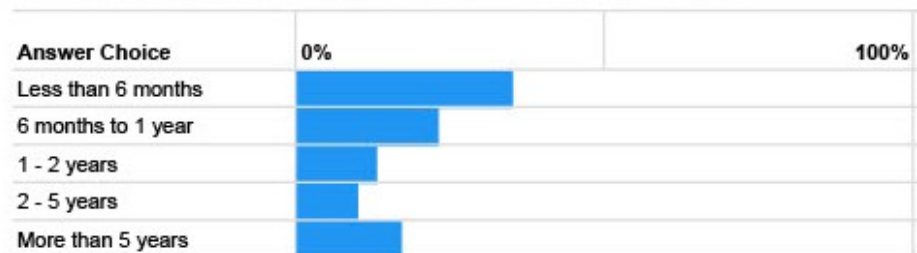
### 2. Age



## How Long Did It Take to Diagnose MC?

MC is often misdiagnosed as IBS or other issues, so we wanted to find out how long it took before a colonoscopy provided the diagnosis. As you can see from the graph, 58% were diagnosed in under a year, but many others suffered for years before learning that they had MC.

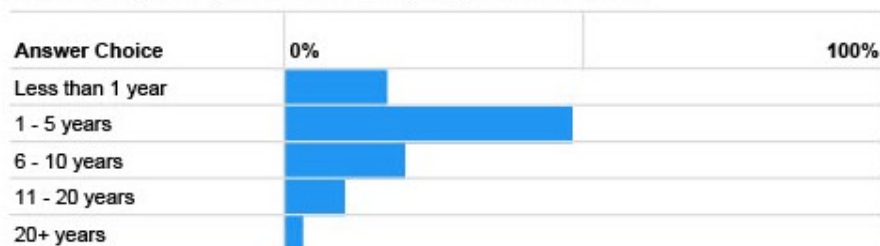
### 4. How long did it take to diagnose MC from start of symptoms?



## How Long Have You Been Diagnosed with MC?

As you can see from the chart, about 65% have been dealing with MC for less than 5 years. But that leaves 35% who are long-term sufferers.

### 5. How long have you been officially diagnosed with MC?

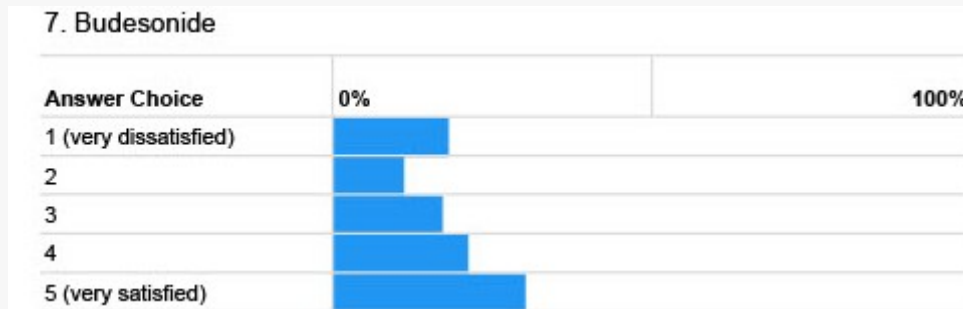


# Medications

Quite a few medications have been prescribed by doctors to treat MC. The survey looked at the most commonly prescribed ones. The survey also asked about the more popular over-the-counter medications and alternative therapies that might help with symptoms.

## Budsonide EC (Entocort)

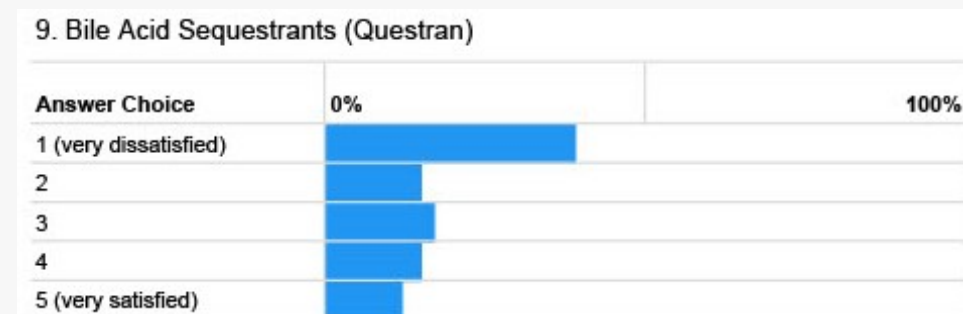
Budesonide is the most commonly prescribed drug for treating MC. It is typically prescribed for a several month course, and then tapered off. But it has issues with relapse of symptoms once stopped. According to our survey, about 78% of the respondents were prescribed budesonide. According to the data, about 51% were fairly satisfied, or very satisfied with the treatment. So that leaves quite a substantial group that didn't have a successful treatment with the main drug prescribed for MC.



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## Bile Acid Sequestrants (Questran)

This drug is commonly prescribed when other drugs fail to give stable remission. It has only been prescribed to about 20% of the respondents. Out of these, only 27% have had a good response. And 54% have been dissatisfied. Based on what has been learned on the Forum, bile acid sequestrants are tricky to use, but can be helpful. There have been several newsletters over the years addressing the topic, and giving advice.

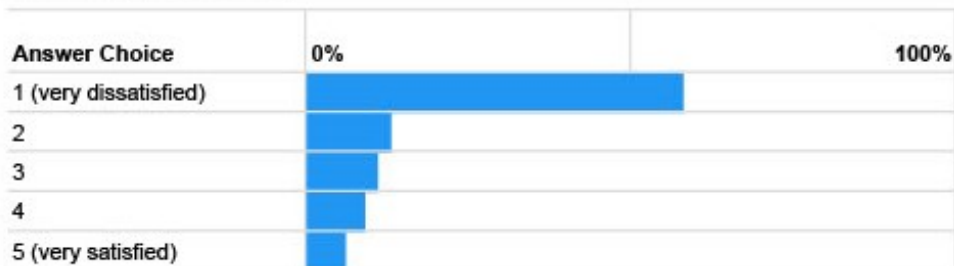


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## 5-ASA (mesalamine)

This drug class used to be prescribed more often for MC, but since budesonide has proven to be superior, it isn't prescribed as much anymore. It has been prescribed to about 20% of the respondents. Out of these, only 15% reported a good response, while 71% were dissatisfied.

### 8. 5-ASA (mesalamine)

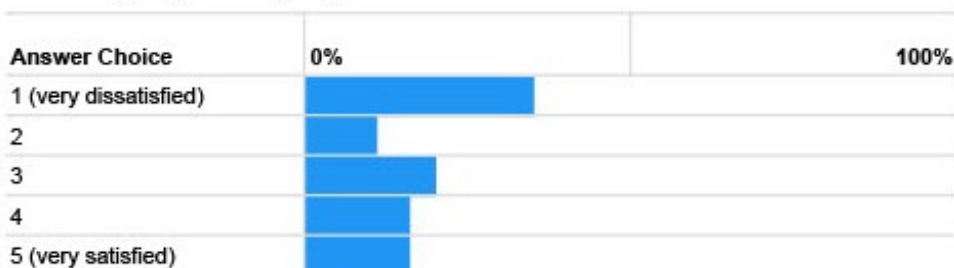


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## Biologics

There has been increasing interest in the use of biologics for treating MC, as they are being used more widely to treat the other IBDs, Crohn's and ulcerative colitis. Only 6% of the respondents have been prescribed biologics. Of this group, 32% reported a satisfactory experience, and 46% were dissatisfied.

### 10. Biologics (Humera, etc)

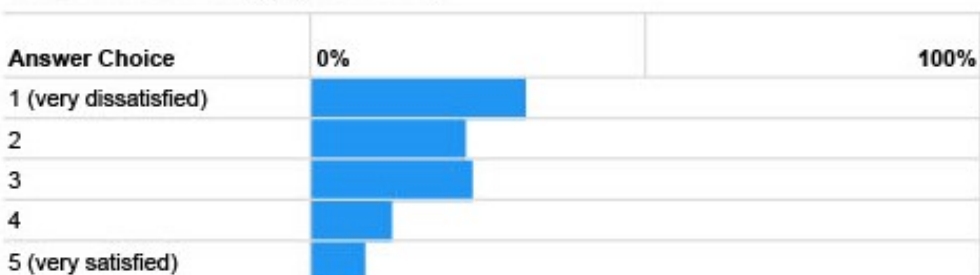


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Next let's take a look at how effective some of the other non-prescription medications and alternative treatments have been. The percentage of respondents who have tried each treatment is given in parentheses after the name of the treatment.

### Bismuth Sulfate (Pepto-Bismol) (51%)

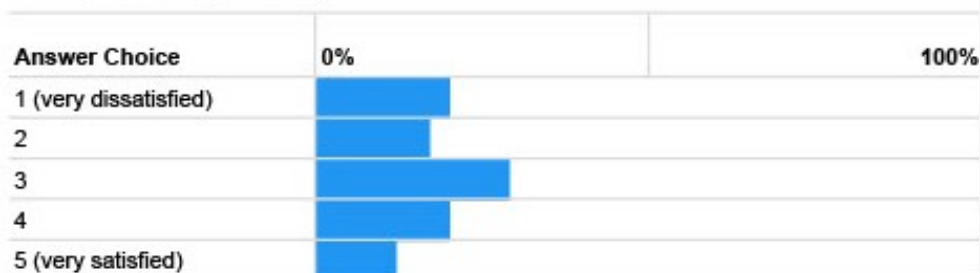
#### 11. bismuth sulfate (Pepto-Bismol)



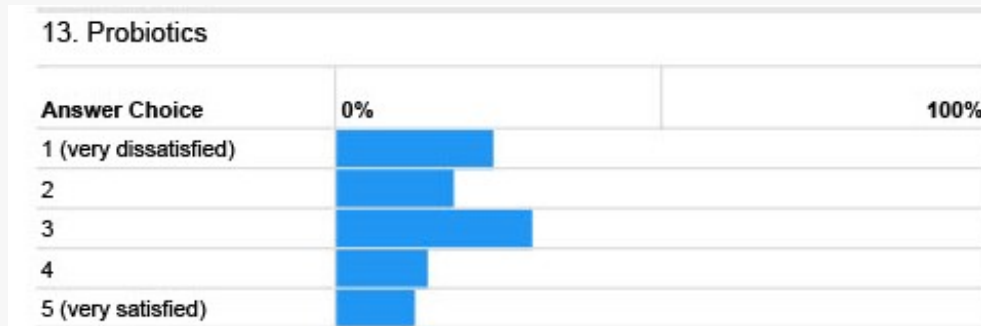
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### Loperamide (Imodium) (65%)

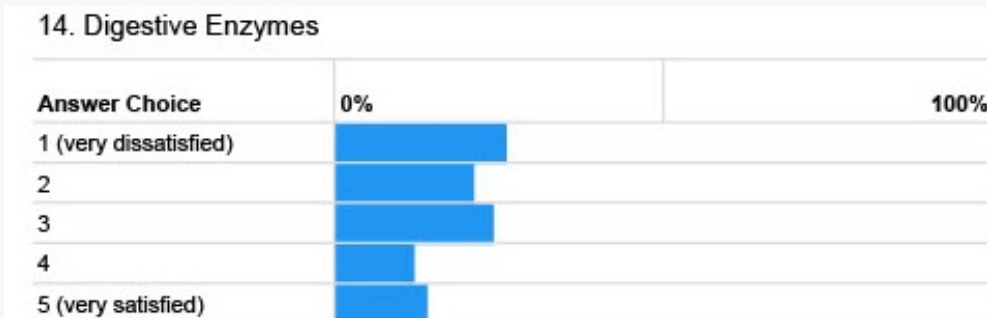
#### 12. loperamide (Imodium)



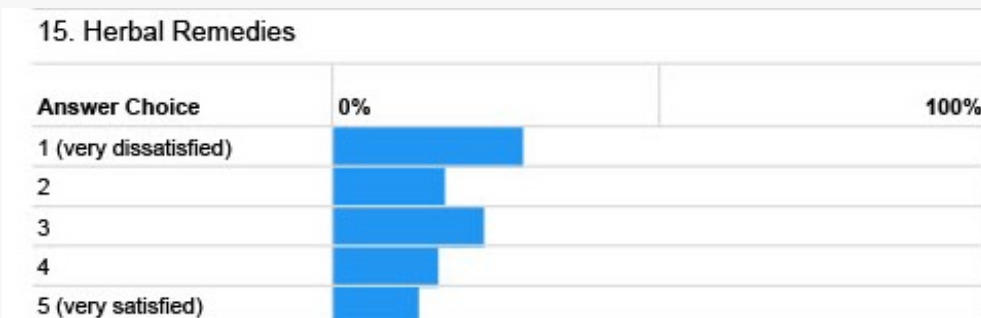
## Probiotics (65%)



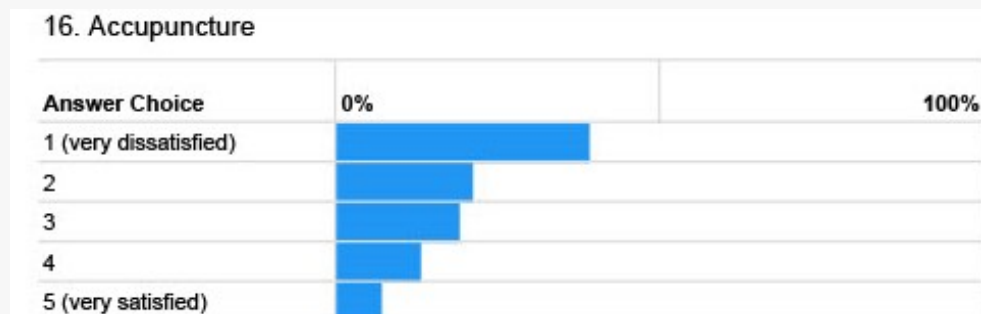
## Digestive Enzymes (33%)



## Herbal Remedies (32%)

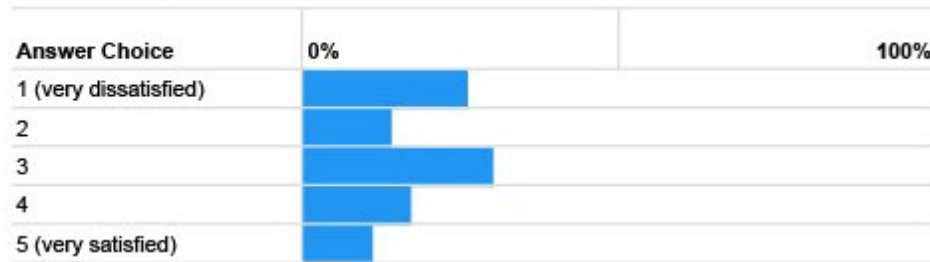


## Accupuncture (15%)



## Yoga and/or Meditation (26%)

### 17. Yoga and/or Meditation



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## Summary of Survey Findings

by Wayne Persky

Even though survey participation was skewed toward female MC patients, with a reduced percentage of responding male patients, (when compared with medical statistics regarding MC gender bias), that shouldn't significantly affect any survey findings, regarding medication use and effectiveness. Medications prescribed to, or selected by, male patients (to treat MC) seem to be very similar to those selected by female patients, based on the many, many shared experiences in the archives of our MC Discussion and Support Forum. And based on that epidemiological evidence, the effectiveness of those treatments appears to be similar, regardless of gender. So presumably, the results of this survey should apply equally to both men and women MC patients.

### Budesonide

Looking at prescribed medical treatments, budesonide is the most popular first line treatment. But published research shows that most MC patients suffer a relapse of symptoms soon after the treatment is ended. Various studies yield different results, but typically, up to 80% of MC patients relapse after the treatment is ended (unless certain diet changes have been made). Extending the dose tapering process past the typical prescribed treatment, by dropping the dose to one 3mg capsule every other day for a week or two, followed by dropping the dose to one capsule every third day for a week or two, etc., can help to prevent the mast cell rebound that triggers a relapse in many cases. Often, taking a daily antihistamine each day, as the budesonide treatment is ended, will also help to maintain remission, by further suppressing mast cell numbers.

### Bile Acid Sequestrants

Bile acid sequestrants show relative low success rates in the survey, but this appears to be because most prescribing doctors don't adequately explain to the patient (or maybe they don't realize) that an effective dose must be determined experimentally, by increasing the dose every week or so until a dose that effectively stops the diarrhea is found. And typically, any food sensitivities must be removed from the diet, before a bile acid sequestrant will be effective. Most patients either can't tolerate the taste and texture of a bile acid sequestrant, or they give up before they discover an effective dose.

### 5-ASA (mesalamine)

5-ASA medications received a low effectiveness rating on the survey, and this matches the evidence found in the archives of our MC Discussion and Support Forum. Mesalamine is a metabolite of mesalazine, and although it has fewer side effect risks, it is only slightly more effective (than mesalazine), for treating IBDs. This is one of the earlier classes of anti-inflammatory medications labeled to treat IBDs, and it was never very effective. It also has the much-despised side effect of causing hair loss, with extended use.

### Biologics

The survey shows that only a relatively few MC patients have been prescribed a biologic, and only about a third of those users report being satisfied with their results. This is probably a reflection of the concerns about the side effect risks of biologic treatments associated with immune system suppression, and the inherent problems associated with biologic treatments that typically result in the body eventually launching an immune system reaction against the biologic agent, thus making the discontinuation of that particular treatment necessary. Although in such cases, another biologic treatment might be effective (or might not), the efficacy is usually limited,

and may last for a few months, to a few years. Even when biologics are effective at reducing the diarrhea, many patients report that all of their symptoms are not resolved.

### **Bismuth Subsalicylate (Pepto-Bismol)**

In its original treatment trials, bismuth subsalicylate (Pepto-Bismol) showed very strong efficacy (75%). The original treatment consisted of eight chewable 262-mg bismuth subsalicylate tablets per day for eight weeks. But since bismuth is a heavy metal, individuals whose body cannot clear the substance from their bodies promptly enough, may suffer a bismuth buildup. And with, or without a buildup, the treatment carries a risk of developing tinnitus (ringing in the ears). The tinnitus, if it develops, usually resolves if the treatment is discontinued soon enough, although in a few cases, it does not. Probably the main reason why the survey results do not reflect a higher success rate, is because these days, most doctors recommend a lower dose than was used in the original treatment when it was published 26 years ago, and those low doses are simply not effective.

### **Loperamide (Imodium)**

Loperamide (Imodium) was first approved by the Food and Drug Administration (FDA) 50 years ago. In that half-century, it has demonstrated that it is one of the safest drugs available. An adequate dose will slow down motility, so that most MC patients using it are able to leave the bathroom long enough to be able to take care of necessary daily errands, without the sudden urgency that can result in an embarrassing “accident”. Probably the most significant risks are the possibility of not taking an additional dose soon enough, if one is needed, and the possibility of an overdose, which can result in cramps and constipation.

### **Probiotics**

The official treatment recommendations of the American Gastroenterological Association Institute specifically advised against the use of probiotics in the treatment of MC, over nine years ago. That said, a few gastroenterologists still recommend probiotics, and a few MC patients do find them helpful. Unfortunately, they make symptoms worse for some MC patients, and for most of us, they seem to make no difference, either way, so whether or not probiotics are helpful, seems to be a very individual issue. That said, probiotics can be very helpful for preventing the development of C diff in certain situations where we find it necessary to take an antibiotic treatment, for example.

### **Digestive Enzymes**

Similar rules seem to apply to the use of supplemental digestive enzymes. Some MC patients claim to be helped by the use of digestive enzymes, while a few others (myself included) suffer reactions if they try to use digestive enzymes. For many of us, using them seems to provide little (if any) benefit. If our gastroenterologist happens to check our pancreatic enzyme production, that test result will often be low when our MC is active. This is because MC can inflame any organ in the digestive system, so many MC patients have an inflamed pancreas, and therefore, reduced pancreatic enzyme production. If you should find yourself in that situation, please don't allow your gastroenterologist to talk you into submitting to a major invasive test or corrective procedure, because this issue virtually always resolves as remission of MC symptoms occurs. Taking a pancreatic enzyme supplement in that situation is usually safe, although it may not be necessary. Until remission of symptoms occurs, and the digestive system can begin to heal, malabsorption of nutrients is going to continue, anyway, because the increased intestinal porosity (leaky gut) is going to persist until after the inflammation is brought under control, regardless of how many supplements we might be taking.

### **Herbal Remedies**

Some of us report that herbal remedies are helpful, and they may well be, but the main problem with using herbal remedies is that many of them have a relatively high level of contamination, according to published research, and the inflammation level associated with MC is so high, that based on their active ingredient levels, it would take roughly a wheelbarrow load (per day) of most herbal treatments in order to come close to the efficacy level necessary to adequately control the inflammation. And, of course, in most cases, there's no way that we could tolerate consuming that much of anything, let alone herbal supplements. But having said that, that doesn't mean that herbal supplements are not helpful. It means that we're probably going to need more than a few herbal supplements in order to get our MC symptoms completely under control.

### **Acupuncture, Yoga, and Meditation**

Treatments such as acupuncture, yoga, and meditation fall under the category of relaxation techniques, and although the survey didn't show widespread use of those practices, or a high success rate, being able to relax can be very useful for lowering our stress level. Stress not only predisposes individuals to the risk of developing MC, but it's also a major component in the perpetuation of the inflammation that prevents us from coaxing the disease into remission. More than a few MC patients have found their stable remission rudely interrupted by a relapse, due to a major stressful event that effectively consumes them, because they're unable to get it off their mind. For the more difficult cases, especially, stress control is typically a very important issue when we're trying to achieve, and maintaining remission.

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