MICROSCOPIC COLITIS NEWSLETTER

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The Story of the Microscopic Colitis Forum and Foundation

Many of us who have visited the MC Forum and foundation website have wondered about how it all got started. Some of us have heard parts of the story, while others have just been focused on healing and simply appreciate it for what it is right now. Only a few “old-timers” know the full story. Those who come here have been impressed with the respect and caring attitude shown by just about everyone. Not all Forums have these qualities, or are able to maintain them over the course of time. We are over 12 years old, a very long time for any forum to remain active and vibrant. The history of our forum helps to explain how this came about.

First Beginnings: Judy Malinowski

The very first internet support group for microscopic colitis was a list serve started by Judy in August of 1995, and called the MC/CC Club. It continued until February, 2003 when she stopped publishing that newsletter so that she could devote more of her time to writing about her passion, scuba diving.

First MC Forum: Sally Read

In the meantime, in 2001 one of the list serve members, Sally Read, founded a discussion board on Yahoo in order to provide a "meeting place" for the people in that group. Many of those on Judy’s list serve also joined the discussion board. When Sally's board began to have problems, some of those who were members of her forum created the current Microscopic Colitis Forum in 2005. Sally joined the new Forum and participated for many years.

Sally was an amazing person. She died in December, 2009 of a heart attack at 68 years old. Here is a sampling from her MC forum tributes page after her death, which you can access here: http://www.perskyfarms.com/phpBB2/viewtopic.php?t=10837

Polly: *I'll bet you had no idea at all about the thousands of MC sufferers you have helped. Without your original vision, this website would not exist and so many of us would still be sick and alone. I'll bet you would be thrilled to know*

that we have members now in Hong Kong, Netherlands, Spain, etc. A worldwide legacy, that's what you have accomplished.

Part of your vision was a firm commitment to respecting each other. You detested those websites where people were rude to each other and were allowed to name-call, insult, and spew hate. From the beginning you set the tone for a caring and compassionate forum - always signing your post with a "Love, Sally". To this day I do that (as do others here), a practice that has probably seemed unusual (to say the least) among newbies. I will continue to do this as a tribute to you.

Maggie: *Without Sally there would have been no Potty People as a family and with her knowledge, caring and guidance she brought us together and was instrumental in forming our family and seeing us through the tough times and the fun times. Some of her original members – I being one – are still together and we have her to thank for that. Without Sally, I would still probably be baffled and terrorized by this disease. She was the only source out there for us who wanted to be proactive in treating our disease.*

Current MC Forum: Wayne Persky

Wayne Persky, or Tex as he is known here, set up the current MC Forum in collaboration with other original members like Polly, Mars and Jean, and has been a principal guiding force over the years. Here is his story.

Back in 2004, Tex had been very sick for about 4 or 5 years, but didn't know what the name of the condition was. He thought he was a celiac, but had no diagnosis from his GI doc, only verification that it wasn't colon cancer. When he found Sally's forum on July 4, 2004 he immediately realized that they were all talking about what he had. He began reading like mad, and decided to join a few days later.

Unfortunately Sally's board was plagued by lack of suitable administration/moderation because the hired administrator was the husband of a member who disrupted the discussions by insisting that diet had nothing to do with treating MC. She and her supporters even set up their own competing forum called The Comfy Place, which died after a couple of years because most people became bored when no one ever improved and stopped posting. They used Sally's forum as a place to recruit new members for their own forum.

At this point, many members of Sally's forum were upset with its management and direction. Tex already had an inactive domain which he originally had used for a food corn business, so he offered to set up a new discussion forum. That is why the website name is www.perskyfarms.com. The founding members hid the forum from public view for a couple of months as they worked on it, and then opened it (allowed public visibility) on May 24, 2005. Polly created the Our History and Mission section and the Welcome Message and Information for

Newbies section. Mars created the Frequently Asked Questions (FAQ), and Jean created all the lists of foods and additives to avoid under the Information on Diet heading. You can see when everyone joined by clicking on the Memberlist.

The forum grew relatively fast at first, more slowly for many years, and recently it seems to be growing faster again. Many visit the forum but don’t join because they either blindly trust their doctors or they aren't willing to commit to strict diet changes. The emphasis on diet when mainstream medicine doesn’t promote it, leads many to dismiss its value. Many of them lurk for years, and then change their minds (and their diet) 4 or 5 years later as they get desperate when the medical merry-go-round fails to provide lasting results. Tex has never bothered with Google analytics to track the number of visitors, and how many of them sign up for the Forum and then actually post. He says that he doesn’t have time to worry about anyone who is not willing to change their diet in order to help themselves. Life is too short to waste it trying to argue with someone who is not willing to accept the accumulated wisdom of many, many MC patients. He says that just guessing, he suspects that for every poster, there are 10–20 who join but never post. And for everyone who joins, there are probably 5–10 who lurk, but don't register an account. He has no idea how many people read a little, shake their heads, and move on.

The approach to treating MC evolved over the past 12 years, based on research progress and the cumulative experiences of the Forum members. We've confirmed that the medical approach only temporarily treats the symptoms without addressing the cause of the inflammation. We've discovered that histamine issues are very important in many cases, so that antihistamines and low-histamine diets may be an important part of the treatment program for some patients. We've found that Budesonide should be slowly tapered when ending a treatment regimen in order to prevent the usual rebound effect that causes relapses. And we've also learned that budesonide can be used long term at lower doses with very little risk of exacerbating osteoporosis if gluten is strictly avoided.

Below are some pictures of get-togethers of Forum members over the years.

Gaea, Peg & Marsha in Spokane, WA

Barbara, Peg, Lou & Carole in NYC

Joe, Scott and Polly enjoying crabs in Maryland

The Potty People Logo

Back when Sally started the first discussion board, they jokingly referred to themselves as the “Potty People”. One of the members, Jean, put together the original version of the Potty Person. This circulated among the members, but was never used as a logo on that web site. When the current MC forum was set up in 2005, there was interest in using the Potty Person on the new website as a logo. It underwent some modifications, with Katy coming up with the “Thinking Potty Person” pose, and Tex adding the toilet paper roll, caption and color scheme. Many other Forum members contributed comments and opinions leading to the final version. The humor and upfront depiction of the MC condition reflect the spirit of the Forum. We may initially be stuck in the bathroom, but we never stop trying to think of new ways to control the symptoms of this disease.

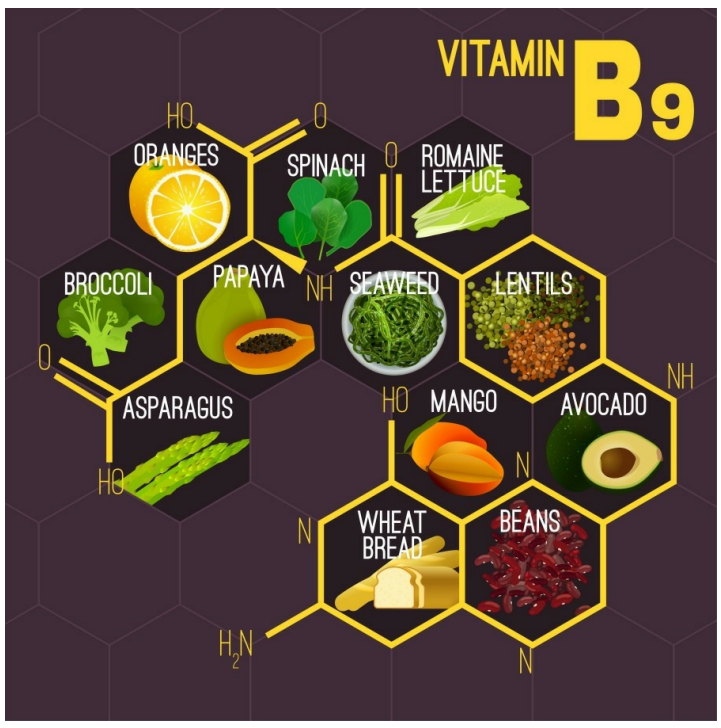
History of the MC Foundation.

Tex has felt for years that someone needs to be advocating for MC patients — the Crohn's and Colitis Foundation has made it clear that they're certainly not interested in doing so. He hesitated to set up an organization for years because he didn’t have the time or the resources to do it right. But finally he decided that if you don't start a project you certainly will never finish it.

So he filed the articles of incorporation with the Secretary of State of the State

of Texas and a few days later, on April 24, 2015, a Certificate of Formation as a Domestic Nonprofit Corporation was granted. After paying $400.00 and filling out and filing a form, tax-exempt status was granted by the IRS on July 23, 2015. He set up the Foundation web site, recruited a Board of Directors, and published the first quarterly newsletter in October, 2015.

Growth so far has been slow. And additional health issues have dampened his enthusiasm. But he feels that if we don't so this, who's going to? It can take many years to grow an organization, so we'll see where it goes. The Crohn's and Colitis Foundation was incorporated in 1965 as The National Foundation for Ileitis and Colitis and later it became known as the Crohn's and Colitis Foundation of America, before finally becoming the Crohn's and Colitis Foundation. At least we've probably picked the correct name to begin with, so that we won't need to change it later.



MTHFR gene mutations and methylation issues they can cause.

by Wayne Persky

The following information is taken from a chapter that discusses methylation issues that are common for microscopic colitis patients that will appear in an upcoming (but as yet unpublished) book about microscopic colitis. Some of the information is paraphrased and some is quoted directly from the text of the book. As the author of the book, I claim the right to be lax about citations from the book in this article. With the legal (copyright) disclaimers out of the way, let's consider how these mutations may adversely affect MC patients.

Methylenetetrahydrofolate reductase (MTHFR) enzyme regulates the methylation cycle, and this enzyme is encoded by the MTHFR gene. MTHFR gene mutations are somewhat common in the general population. Actual numbers are widely-debated, but in 2003, when the Human Genome Project was completed, it was discovered that over half the population has one or more mutations of the MTHFR gene (some estimates run as high as 60 %), but so little is known about this whole issue that most people wonder what effects (if any) these gene mutations might have on them.

Because this is such a complex subject and so little is actually known about it in general, it's not surprising that little is known about how this issue might affect MC patients. While researchers have only explored the tip of the iceberg regarding the MTHFR gene, they have sorted out a few associations with various aspects of health, and that allows us to speculate about how some of these SNPs might affect a disease such as MC.

When one's MTHFR gene is healthy, these are the important chemical processes that it initiates.

The first step is the production of the MTHFR enzyme. This enzyme breaks down vitamin B-9 (known as folic acid), and transforms it from 5,10-methylenetetrahydrofolate into 5- methylenetetrahydrofolate. The 5-methylenetetrahydrofolate is used to convert homocysteine into methionine, which is then used by the body for making various proteins, using antioxidants, and processing fats.

Methionine can be used to help suppress inflammation and depression symptoms. In the liver, methionine is converted into s-adenosylmethionine (SAM-e). SAM-e is also an anti-inflammatory agent. It is used in the production and subsequent breakdown of neurotransmitters such as serotonin and dopamine; and melatonin, which is a neurotransmitter-like compound. SAM-e is also important in the repair and maintenance of cells. Note that if more detailed information is desired, it can be found online at the stopthethyroidmadness.com webpage.[1]

And here is what can happen when the MTHFR gene is mutated.

When the MTHFR gene is defective, the MTHFR enzyme that's produced performs at only 70 % or 40 % of its normal capacity, depending on the nature of the gene mutation. This can cause compromised ability of the body to break down and eliminate toxins and heavy metals, and it can lead to a buildup of certain heavy metals. The defective enzyme may not be able to break down and convert folate or folic acid properly, resulting in a buildup of homosysteine, which increases the risk of coronary heart disease and related issues. It can also increase the risk of developing dementia.

Homocysteine conversion to methionine may be compromised, raising the risk of arteriosclerosis, fatty liver disease, anemia, and inflammation. SAM-e production will be decreased, resulting in the likelihood of increased depression symptoms. Because the inactive forms of folate and vitamin B-12 cannot be properly converted into the active forms so that the body can utilize them, the inactive forms of folate and vitamin B-12 may accumulate and this can cause levels to test high, even though the body may be starving for the active forms of the vitamins. The risk of developing certain cancers may increase. Many diseases have been associated with one or more mutations of the MRHFR gene.

Because genetic mutations can be inherited from both the mother and the father, there are many possible combinations of mutations. The two mutations that are likely to have the most serious effects on one's health are known as C677T and A1298C, referring to the type of DNA changes which are called “SNPs”. Sometimes they are written as just 677 and 1298, because these numbers refer to their location on the gene. If an individual has two copies of either the 677 or the 1298 mutation, it means that that person received one SNP from each parent and he or she is said to be homozygous for that particular mutation. If an individual has one copy of either the 677 or the 1298 mutation from either parent, plus a normal gene that was inherited from the other parent, that person is considered to have a heterozygous mutation.

23andMe is at the forefront of genetic analysis services that are easily available to the general public.

If you would like to find out which SNPs (if any) you might have, probably the easiest (and most economical) way to find out is to order the test offered by

23andme.com.[2] We are not recommending their services, we're just pointing out that they are available. The Microscopic Colitis Foundation has no affiliation with 23andme.

Associated websites such as geneticgenie.org offer a free methylation analysis of your raw data from 23andme to enable you to easily see how you might be affected by your MTHFR gene mutations.[3] And for a nominal fee, sites such as promethease.com offer services that will analyze your raw data from 23andME and provide various reports, including some that describe your statistical odds of developing certain diseases as a result of your genetic mutations.[4] And there are many other services offered by other companies that will provide an analysis of your raw 23andMe data. Some reports are free while others are available for a fee. Examples can be found at websites such as livewello.com, codegen.eu, nutrahacker.com, infino.me, enlis.com, and geneknot.com.[5,6,7,8,9,10]

Do you know the difference between folate and folic acid?

Even many health professionals will argue that the two terms are interchangeable. But they are not. According to the DesignsforHealth.com website [11]

The terms "folate" and "folic acid" are often used interchangeably but they are not one and the same. Folates are members of the B vitamin family (referring to various tetrahydrofolate derivatives) naturally occurring in foods, mainly leafy green vegetables. Folic acid, on the other hand, is a fully oxidized, synthetic compound (pteroylmonoglutamic acid), used in dietary supplements and in food fortification. The important difference to note is that folic acid does not occur naturally.

Supplement with the active forms of B vitamins.

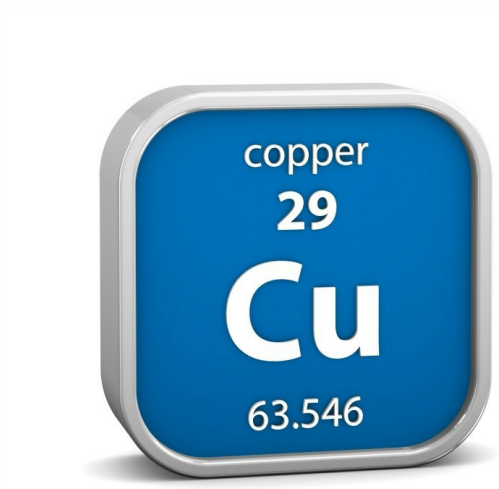
It's not possible to repair a defective gene, but you can certainly help it to function better. In the event that you have methylation issues (compromised ability to convert folate and vitamin B-12 into the active forms), you will probably benefit from supplementing with the active forms of folate (5-methyltetrahydrofolate) and vitamin B-12 (methylcobalamin) rather than using the inactive forms.

Due to the fact that the active form of vitamin B-6 is used to activate diamine oxidase enzyme (which the body uses to help purge excess histamine that has accumulated), supplementing with the active form of vitamin B-6 can help to manage histamine levels in the body. For someone who has methylation issues, the proper form to use would be the methyl version of vitamin B-6, which is called pyridoxal-5-phosphate, or (P5P).

Over-methylation (which is called histapenia) is possible.

Symptoms of over-methylation may include head or neck pain, fatigue, irritability, anxiety, insomnia, depression, paranoia and a tendency to ponder on thoughts. Over-methylated people have elevated levels of serotonin,

dopamine, and norepinephrine, and a low histamine level in their blood They tend to be very creative, but they may overreact to common situations in life. Over-methylated individuals also tend to have many food sensitivities, but they are not as likely to react to seasonal allergies. If you suspect over-methylation, it may help to reduce or stop taking methylating supplements, at least for a while. Some authorities suggest that taking 50 mg time-release capsules of niacin may help if the over-methylation is caused by taking methyl "B" vitamins.



People who have MTHFR mutations often show a high level of copper.

This will usually cause a low level of zinc. The ratio of these two metals is important, but when copper is high, hyperactivity, depression, headaches, acne, poor immune system functioning (resulting in frequent colds), skin sensitivity (easy bruising), low thyroid functioning, or adrenal stress may be a problem. And high copper can frustrate efforts to raise iron levels.

Copper levels can usually be lowered by taking vitamin C, but this should be done slowly, to minimize detoxing symptoms. Taking zinc can also help, but the same precautions regard going slowly should apply.

Methylation issues appear to be associated with MC, based on the observation that so many MC patients seem to have histamine-related issues.

Statistically, it's unknown whether MC patients are any more likely than someone in the general population to have MTHFR mutations, but it appears that they may be more likely to experience symptoms because of their level of inflammation due to the disease. Under-methylation (IOW a deficiency of methyfolate) interferes with the production of SAMe, and one of the functions of SAMe is to rid the body of excess histamines. Many MC patients have problems with excess histamine. Experience (and epidemiological data) shows that supplementing with Histame almost never provides any substantial benefits. Histame is sold to replace DAO, and in theory at least, it should be capable of reducing the level of residual (unused/left-over) histamine and therefore prevent histamine levels from reaching problematic levels in the body. Why doesn't it work? Perhaps it doesn't work because the main problem is due to under-methylation. Maybe it doesn't work because SAMe has a much more potent effect on histamine levels than DAO.

Likewise, relatively few MC patients report any significant benefits from taking Gastrocrom. Gastrocrom is sold as a mast cell stabilizer, and it's claimed to help prevent the inappropriate degranulation of mast cells (which results in the dumping of histamine and other pro-inflammatory agents into the bloodstream). Gastrocrom is sometimes prescribed to treat mast cell activation disorder (MCAD), which is known to cause the inappropriate degranulation of mast cells. But again, Gastrocrom is usually reported to not be beneficial in the treatment of MC patients out in the real world. And as is the case with Histame, perhaps this is because SAMe is the primary regulator of histamine levels in the body, and so as a result, products such as

Gastrocrom, that do not enhance the production or functionality of SAMe cannot have a significant effect on histamine levels in the body.

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