One of the most difficult aspects of living with MS is the disease’s unpredictability. Many people with MS find that healthy lifestyle habits, like exercise and eating nutritiously, help them feel better overall. There is no consensus or guidelines to follow when it comes to what a person with MS should eat. However, there is evidence to support that eating certain foods and nutrients and avoiding others may help with MS symptoms and disease activity. A number of diets have been proposed as treatments, or even cures, for MS. There is insufficient evidence to support any one of them (and no diet will cure MS), however, there are potential benefits in a few. Our first article covers several dietary strategies for people with MS, including the scientific evidence to support, or refute, them.

Dietary supplements may be an attractive option for people with MS in their efforts to manage the disease and its symptoms. Several vitamins, minerals and herbs are thought to be beneficial in MS. However, being educated and careful about their use is very important. Many supplements contain active ingredients that can have strong effects in the body. Some may cause side effects or harm when taken in combination, at high doses, or when taken instead of prescribed medications. Others have the potential to interact with prescription drugs in ways that might cause problems. Learn more about dietary supplements and the scientific evidence surrounding their benefit in MS.

The Healing Meals Community Project is a nonprofit organization based in Bloomfield, CT, with a dual mission. They provide healthy, organic meals to clients and their family members in and around the greater Hartford community who are undergoing treatment for serious illness. Their mission is to not only help clients logistically during a difficult time, but also to teach them through direct experience that organic, nutrient-rich food sustains and supports health. Youth volunteers play a key role in each step of the process, including food procurement, preparation and packaging. Read more about the good work this organization does, and the ripple effect it has, not only in the lives of the clients they serve, but also in the lives of their youth volunteers.
Samantha Leathers was diagnosed with MS in 2017, when she was 27 years old. Seven months ago, she started her Instagram account, Unwell Adventures to share her MS journey with others who may be struggling in similar circumstances. She began by posting stories from her first year when she was experiencing MS flares, as well as things that were helpful in that difficult time. Samantha hopes to give a voice to a generation of MSers in their late 20’s through her Instagram, and provide more relatable resources for families living with the disease. She also hopes that Unwell Adventures will help to bolster her followers’ morale. Samantha not only offers support to others through her Instagram, but has also found it to be a great source of encouragement herself. Find out more about Samantha’s inspirational story and her mission to use social media to help those newly diagnosed with MS.

Our Repository Spotlight focuses on the work of Dr. Robert Clark at the University of Connecticut School of Medicine. Dr. Clark is studying changes in the microbiome that may cause the abnormal response of immune cells in people with MS. This research may lead to a better understanding of the causes of MS, as well as reveal new therapeutic targets.

Our iConquerMS Spotlight reveals some interesting data collected from REAL MS participants about which vitamins, minerals and supplements they are taking, and which they find most helpful. Data like these are a growing and powerful resource for MS research, providing investigators and clinicians with real-life information on what living with MS is like. Stay tuned for the next round of REAL MS surveys, due to be released this month! If you haven’t already done so, please join iConquerMS today and add your voice to those already helping to steer the future direction of MS research!

We hope you enjoy our newsletter and encourage you to share it with anyone you think may be interested in learning more about ACP.

Jan and Lindsey, on behalf of the Accelerated Cure Project Team

**MS Diets – Is there enough evidence to recommend any of them?**

A nutritious, well-balanced diet combined with other healthy lifestyle choices (exercise and refraining from smoking) is the foundation of good health not only for people with MS, but also for the general public. Healthy eating includes foods that are rich in fiber and low in saturated fat, such as lean proteins, whole grains, vegetables and fruit. The foods you should avoid are just as important, such as processed foods, as well as those high in sugar and salt. Eating in this manner helps the body’s everyday functions, promotes optimal body weight and can help with disease prevention. While there is no specific diet that will prevent or cure MS, there is evidence to
support that eating certain foods and nutrients, and avoiding others, may help a person’s MS symptoms and disease activity.

A recent study shows that diet can influence the course of inflammatory diseases in two ways. Dietary factors can directly impact the metabolic process of inflammation in cells. What you eat can also change the mix of “good” and “bad” bacteria in the digestive tract (the gut microbiome). A healthy digestive tract is populated by a great number of microorganisms living in balance. A disruption of this balance can have a significant impact on one’s health, specifically the chronic, systemic inflammation that occurs in diseases such as MS.

Nutrition is a hot topic in MS research. Many studies reveal an added benefit for people with MS to the “usual” benefits of adhering to a healthy diet. For example, there is evidence that sodium (the primary component of salt) increases MS disease activity. In an observational study, people with MS who consumed a moderate or high amount of sodium had a higher rate of relapses and a greater risk of developing a new lesion on MRI than people who consumed a low amount of sodium. Another study shows that consumption of saturated fats (found in such foods as red meat and full-fat dairy products) not only increases the risk of developing MS, but is also linked to disease progression. In addition, a study published in February 2018 found that people who have MS are at an increased risk for heart problems compared to those who don’t have MS, adding more weight to the conclusion that people with MS should steer clear of saturated fats, as well as sweetened foods (which also negatively impact heart health). High sugar intake is also associated with weight gain. Research findings point to obesity as a possible risk factor for MS. Excess weight can also make it more difficult for those living with MS to be mobile and perform activities of daily living. In addition, obesity increases fatigue, which is a common symptom of MS. Interestingly, one study suggests that drinking cow’s milk may be linked to MS prevalence, however these results have not been confirmed.

According to the Harvard School of Public Health, certain foods may affect inflammation, either positively or negatively. For example, those that may cause inflammation include fried foods, sugar-sweetened beverages, red meat, processed meat and margarine. Some anti-inflammatory foods might include tomatoes, olive oil, green leafy vegetables, fatty fish, fruits and nuts (especially walnuts). This school of thought suggests choosing the right anti-inflammatory foods may decrease the risk of illness. Consistently picking the wrong ones may accelerate the inflammatory disease process.
Several diets have been proposed as treatments, or even cures, for MS. It’s important to note that, while they may provide some symptomatic benefit, most have not been subjected to rigorous, controlled studies, and the few that have been evaluated have produced mixed results.

The Paleo diet gained popularity with Dr. Terry Wahls, a woman with secondary progressive MS that was wheelchair-dependent. However, after consuming a modified Paleo diet (along with physical therapy and neuromuscular electrical stimulation), she was able to walk again. The aim of the Paleo diet is to return to a way of eating that’s more like what early humans ate. The reasoning is that farming changed what people ate and established dairy, grains and legumes as staples in the human diet. According to the hypothesis, the human body has not been able to adapt to this change. While there are many variations of the Paleo diet, the commonly recommended foods are fruits, vegetables, nuts and seeds, lean meats, fish, and oils from fruits and nuts. Foods to avoid eating are grains, legumes, dairy products, refined sugar, salt, potatoes and highly processed foods. There isn’t much scientific evidence to support this diet’s role in MS. One study showed that the Paleo diet improved MS fatigue in people with secondary progressive MS, but the study was small and other interventions like stretching, massage, and meditation were used along with diet. As a result, it’s hard to determine which of the interventions benefitted study participants.

The Mediterranean Diet (MD) is based on the traditional foods that people used to eat in countries bordering the Mediterranean Sea (such as Italy and Greece). It is known to be beneficial for people with heart disease and Type 2 Diabetes, and possibly prevents cancer. This diet promotes a low consumption of added sugar, refined grains, trans fats, refined oils, processed meat, and other highly processed foods. The MD includes a moderate intake of red wine, and a high consumption of whole grains, vegetables, fruits, nuts, seeds, legumes, potatoes, breads, olive oil, and fish. A small 2016 study found that people who adhered to a MD had a lower risk for developing MS. Otherwise, there is no strong evidence linking its benefit to people with the disease.

The McDougall diet is based on the premise that the rich Western diet is the cause of several chronic diseases. It aims at eliminating animal-based food, as well as vegetable fats, and replacing them with low-fat plant-based foods. The suggested staples of the diet include wheat flour products, corn, rice, oats, barley, quinoa, potatoes, sweet potatoes, beans, peas, and lentils, fresh fruits and non-starch green or colored vegetables. This diet requires low sodium and sugar intake and consumption of dairy, oils, eggs, meat, poultry and fish is not allowed. There is no evidence that the McDougall diet provides benefit in MS or other autoimmune diseases. However, a study from the McDougall Health & Medical Center showed that 7 days of the diet led to a reduction in weight, blood pressure, and cholesterol levels. This study did not look at on the long-term effects of the diet.

A study published in March 2011 found a higher incidence of celiac disease, an autoimmune disease characterized by gluten intolerance, among people who have MS than among the general
population. Gluten is a protein found in wheat, barley, and rye. People who have celiac disease must avoid gluten entirely to avoid intestinal damage, but many people who don’t have celiac disease find they feel better overall when they adhere to a gluten-free diet. While there’s no evidence to suggest that avoiding gluten is beneficial for people with MS who don’t also have celiac disease, it may be an option for those not finding relief with other things.

The **Ketogenic Diet** is a very low carbohydrate diet designed to force the body to burn fat instead of glucose for energy. This process produces ketones (which gives this type of diet its name). Key foods include avocado, full-fat cheeses, heavy cream, butter, whole eggs, fatty nuts and seeds, bacon, beef, fatty fish, low carbohydrate vegetables, and olive oil. The Ketogenic Diet has been used to treat epilepsy since the 1920s. Researchers are examining its potential use for treating other neurological disorders, like MS. The resulting change in the body’s metabolism from glucose to fat is thought to improve the function of mitochondria, which is linked to the survival of nerve fibers. Because nerve fibers degenerate and die in progressive MS, scientists believe a Ketogenic Diet may benefit people with progressive forms of the disease. Further research is necessary in order to confirm this effect.

The **Fast Mimicking Diet** (FMD) follows the same general principles as regular fasting. The body is deprived of food in order to take advantage of health benefits like reduced inflammation and fat burning. The primary difference is that instead of eliminating all food for a single set period of time, calories are restricted for five days every one or two months. While some variation exists, the amount of food on the first day of the fasting period is typically restricted to 1,100 calories, consisting of 34% carbohydrates, 10% protein and 56% fat. For the remaining four days, calories are typically restricted to 800 per day with a content ratio of 47% carbohydrates, 9% protein and 44% fat. A recent study found that periodic 3-day cycles (3 days of fasting every 7 days for 3 cycles) of a FMD were effective in relieving symptoms in a mouse model of MS. In fact, there was a complete reversal of symptoms in 20 percent of the animals. It’s important to note, however, that more research is needed to determine the role of fasting in humans with MS.

Dr. Roy Swank described the **Swank diet** in the mid-1950s. The Swank diet is low in fat, with no more than 15 grams of saturated fat permitted per day and no more than 20 to 50 grams of unsaturated fat and oils. Foods that are allowed on the diet include whole grain cereals and pasta, fruits and vegetables, white fish and shellfish, as well as skinned, trimmed poultry. Swank diet guidelines also recommend one teaspoon of cod liver oil and a multivitamin every day. Red meat is not allowed the first year, and is limited to three ounces weekly thereafter. Processed foods and dairy products that contain more than one percent of butterfat are also not allowed. Dr. Swank recommended this diet to MS patients under his care for several years, many of which followed the diet. Dr. Swank collected data from those patients on the diet and reported his results in 1970. These results were published in 1990. Dr. Swank’s data suggest the diet...
reduces occurrence of relapses, accumulation of disability and mortality in people with MS. It is important to note that Dr. Swank’s study did not have a comparison arm following healthy control subjects. Also, a standardized scoring system, like the Expanded Disability Status Scale (EDSS), was not available at that time, making quantifying the degree of disability and, in turn, comparing groups of MS patients challenging. Other researchers have not duplicated Dr. Swank’s results, so there is no scientific proof that the Swank diet really controls MS. However, there is anecdotal evidence from people with MS who say this diet makes them feel better.

Overcoming MS (OMS) is a nonprofit organization whose mission includes empowering people with MS by providing them with the tools and resources they need to make sustainable changes to their diet and lifestyle in order to live longer, healthier lives. Their Recovery Program includes a modified version of the Swank diet that takes into consideration more recent data on dietary fats. Amanda Windhof, a member of the iConquerMS research committee and the lead of ACP’s Next Steps Committee on nutrition, is a firm believer in the OMS lifestyle. For those interested, Amanda shares recipes that fit the OMS program on her website. In her words, “I share recipes that fit the Overcoming MS lifestyle in hopes that others will see healthy food does not mean lacking in taste.”

While many different dietary strategies are being promoted for people with MS, currently there is insufficient evidence to recommend any of them. Interestingly, despite their differences, these diets have several themes in common. Almost all advocate avoiding highly processed food, food that increases blood sugar levels and food that is high in saturated fat. Most diets also recommend reducing consumption of fatty red meat and increasing consumption of fruits and vegetables. It is important to consult with a doctor or nutritionist before making significant changes in the foods that you eat. One concern about adopting a specific diet is that it may be too restrictive, meaning a person may end up being deficient in important nutrients, causing more harm than good. More research surrounding dietary strategies in MS is needed to determine their benefit and risk. These studies are underway, an exciting development as diet is a factor that is easily controlled, giving people with MS some power over the disease.
**Dietary Supplements in MS – Do They Help?**

According to Merriam-Webster, a dietary supplement is defined as “a product taken orally that contains one or more ingredients that are intended to supplement one’s diet and are not considered food.” This includes vitamins, minerals, herbs, amino acids, enzymes, and many other products. With the exception of vitamin D (which will be discussed later), researchers believe it is best to get the nutrients your body needs from eating a healthy, balanced diet. Even though synthetic vitamins are made to have the exact chemical composition of naturally occurring ones, food is a complex source of nutrients that all work together. In contrast, dietary supplements tend to work in isolation. In addition, while some supplements may help supply adequate amounts of essential nutrients, it’s important to remember they can’t take the place of the variety of foods that are important to a healthy diet.

Vitamins are classified in two groups. **Water-soluble vitamins**, as the name implies, dissolve in water and are not stored in the body. This group includes all of the B vitamins and vitamin C. If an individual consumes more of a water-soluble vitamin than they need, the excess is excreted. Because they are not stored in the body, people that choose to take them should do so regularly. **Fat-soluble vitamins**, on the other hand, dissolve in the fat tissue of the body and are stored there until the body needs them. This group includes vitamins A, D, E and K. Because fat-soluble vitamins can build up in the body, it’s important not to consume too much of them.

Vitamins or minerals taken at a certain dose may be beneficial. However, taken at a higher dose, the same vitamin or mineral may be harmful. The [Food and Nutrition Board](https://www.nap.edu) of the National Academy of Sciences has established a recommended daily allowance (RDA) for vitamins and minerals. This represents the minimum amount of a nutrient per day necessary for maintenance of good health. In general, it is important to discuss which supplements are most appropriate (including dosage) with your healthcare team before taking them, just as you would any other medication.

In the United States, dietary supplements are not evaluated by the Food and Drug Administration (FDA) for safety and efficacy in the same rigorous way that medications are. Because of this, labels on these products are not permitted to make specific claims about their ability to treat or cure any particular illness. Manufacturers of supplements are not required to prove the effectiveness of their products, or accurately report what is contained in them. As a result, supplements may vary widely in both the amount and quality of their ingredients.

A number of vitamins, minerals and herbal supplements are of interest in MS. However, it is important to note that there is a lack of sufficient evidence to make recommendations regarding the effectiveness and safety of any
of them for all people with MS. In general, any supplement that claims to boost or improve the immune system should be avoided because MS is an autoimmune disease in which the immune system is already “hyperactive.”

Vitamin D is important for absorption of calcium and for bone growth, and has an important role in cell, neuromuscular and immune function. There are two main forms of Vitamin D, which are D2 (also known as ergocalciferol) and D3 (known as cholecalciferol). Regular sun exposure is the most natural way to get enough vitamin D, however, too much sun is associated with health risks. Dietary sources include fish, cheese, mushrooms and egg yolks. Some foods that don’t naturally contain vitamin D are fortified with this nutrient, such as milk and some breakfast cereals. Supplements can also help increase intake, in which case vitamin D3 is generally considered the preferred form. The RDA for vitamin D is 600–800 international units (IU) for adults. The generally accepted safe upper limit for daily vitamin D intake is 4,000 IU, however higher amounts may be recommended based on specific circumstances. Symptoms associated with vitamin D toxicity may include a buildup of calcium in your blood (hypercalcemia), which can cause nausea and vomiting, weakness, frequent urination, bone pain and the formation of kidney stones. Research shows higher vitamin D intake and higher vitamin D levels are associated with lower risk of developing MS as well as reduced disease activity. People with MS are also at increased risk for bone loss (osteopenia and osteoporosis), for which vitamin D supplementation may be of benefit. People with MS should talk with their healthcare providers about whether blood testing of vitamin D levels and supplementation would be of benefit.

Antioxidant vitamins decrease the damage caused by oxidants or free radicals. A free radical is a molecule in the body that has an unpaired electron. These molecules are very unstable because they are constantly trying to pair their unpaired electron. This causes them to react with other cells in the body, resulting in oxidative damage. Free radicals contribute to illness and aging. Studies suggest that the damage caused by free radicals may be involved in the disease process in MS. However, there are no well-documented published studies of people with MS that show a clinical benefit related to antioxidant supplements. In fact, this class of vitamin is known to stimulate the immune system, which (as mentioned earlier) is not recommended for people with MS.

**Antioxidant Vitamins**

Vitamin A is important for maintaining healthy vision and proper function of the immune system, among other things. Dietary sources include cod liver oil, eggs, as well as orange and yellow vegetables and fruits. The RDA for men and women ranges from 2,300 to 3,000 IU and daily intake should not exceed 10,000 IU. Pregnant women, in particular, should not consume high amounts of vitamin A, as there is evidence this may produce birth defects. In MS, research shows vitamin A does not play a role in the disease course of RRMS.

Vitamin C, also known as ascorbic acid, is necessary for the growth, development and repair of all body tissues. It’s involved in many body functions, including the immune system. Vitamin C is readily available in foods such
as citrus fruits and tomatoes. The RDA for this vitamin is 90 milligrams (mg) for men and 75 mg for women. Interestingly, the RDA for smokers includes an additional 35 mg. Daily doses greater than 2,000 mg may cause diarrhea or even kidney damage. Researchers have long believed that vitamin C may be useful in helping prevent urinary tract infections, which frequently occur in people with MS, by making urine more acidic and making it more difficult for bacteria to colonize the urinary tract. However, recent research indicates that vitamin C does not acidify urine. There is more evidence to support the use of cranberry to prevent urinary tract infections than there is for vitamin C (see the herb section of this article). With regards to this vitamin’s role in the treatment of neurological diseases such as MS, researchers have found it to have benefit in animal studies, however it hasn’t been studied sufficiently in humans to make a definitive conclusion.

Vitamin E plays many important roles in the body, including helping to keep the immune system strong against viruses and bacteria. It can be found in such foods as vegetable oils, nuts, seeds and green leafy vegetables. The RDA for vitamin E is 22 IU for both men and women. A diet high in polyunsaturated fatty acid (PUFA), which is thought to be beneficial in MS, increases the RDA by approximately 0.9–1.3 additional IU of vitamin E for each additional gram of PUFA consumed. Daily vitamin E doses greater than 1,500 IU should be avoided. One study identified an increased mortality among consumers of 400 IU or more of vitamin E. Another study shows vitamin E may increase the risk of lung cancer in people that smoke. With regards to MS, Norwegian researchers found that increased levels of vitamin E are associated with reduced odds for MRI-detected disease activity in RRMS patients undergoing interferon beta-1a treatment.

Vitamin B6, also known as pyridoxine, helps to maintain a healthy metabolism, as well as healthy skin and eyes. This vitamin also supports nerve and liver function. Foods rich in vitamin B6 include fish (especially salmon and tuna fish), pork, chicken, beans and bananas. The RDA for vitamin B6 is 1.3–1.7 milligrams for adults ages 19–50. It’s important to note that high doses of pyridoxine can cause nerve symptoms that mimic MS, such as numbness, tingling or pain. These symptoms are reversible once supplementation is decreased.

Vitamin B12, also known as cobalamin, is key to the normal function of the brain and nervous system. It is also involved in the production of red blood cells and DNA, the genetic material in all cells. Vitamin B12 is naturally found in animal products, such as fish and organ meat, but not in plant-based foods. Fortified breakfast cereals are another potential source. The RDA for cobalamin is 2.4 micrograms for both men and women. Research suggests that people with MS may have low levels of vitamin B12, compared to the general population, indicating there may be a relationship between the two. Vitamin B12 deficiency can be evaluated through a blood test. People with MS who have low levels might benefit from vitamin B12 supplementation. For people with MS with normal levels, there is no evidence that vitamin B12 supplementation either improves neurological symptoms or favorably alters the course of the disease.

Minerals are inorganic nutrients. Macrominerals are the minerals your body needs in large amounts, such as calcium and magnesium. Minerals needed in only small amounts are called trace minerals.
Minerals

Selenium is a trace mineral that has antioxidant effects, and it also plays an essential role in the production of thyroid hormone. Good sources include legumes, seafood, whole grains, lean meats, and dairy products. For those 14 years of age and older, the RDA of selenium is 55 micrograms. Toxic effects may occur with daily doses greater than 400 micrograms. Given its antioxidant properties, selenium may also stimulate the immune system, which, as mentioned earlier, is already overactive in people with MS. Research suggests that selenium levels may be lower in people with MS than in the general population, however it is unclear whether selenium supplements would benefit those with MS.

Calcium is the most abundant mineral in the human body. It plays a key role in the formation of teeth and bone, as well as muscle contraction, transmitting messages through the nerves and the release of hormones. Dietary sources of calcium include dairy products, leafy vegetables, and eggs. The RDA for adults is 1,000–1,200 mg of calcium per day. Calcium taken in excess amounts (more than 2,000 mg) may result in toxic effects. There is no scientific evidence to support the once held hypothesis that consuming large amounts of calcium during childhood (milk and other dairy products) followed by a sudden decrease in consumption at adolescence causes MS. However, people with MS are at increased risk for bone loss (osteoporosis), so adequate calcium intake is crucial.

Zinc is a trace mineral needed for a healthy immune system. It plays a role in cell division, cell growth, wound healing and the breakdown of carbohydrates. Zinc is also needed for the senses of smell and taste. Meat and shellfish are excellent sources of zinc, as are whole grains and dairy products. The RDA for zinc is 11 mg for men and 8 mg for women. High intake of zinc can result in copper deficiency, which may result in MS-like neurologic symptoms. A recent study in an animal model of MS suggests that zinc is involved in spinal cord demyelination and in generation of motor deficits. More research is needed to demonstrate these effects in humans.

An herb is a plant, or part of a plant, that can be used for medicinal purposes. Herbs, like drugs, interact with the cells of the body and can sometimes produce changes in body processes. It is important to recognize that there are many unknown aspects to herbs. Their effects may be beneficial, but they can also be harmful. Herb users should be aware of proper dosing, potential side effects, and how the herbs consumed may react with drugs, as well as other herbs.
Herbs

Ginkgo Biloba comes from one of the oldest tree species and has been used in China for medicinal purposes for thousands of years. Ginkgo is a known antioxidant. It also inhibits a substance known as platelet activating factor, which in turn causes a decrease in the activity of certain immune cells. This mechanism of action is why some recommend this herb as a therapy for MS. Recent clinical studies surrounding the therapeutic benefit of this herb have had mixed results. One suggested a benefit with regards to fatigue, symptom severity and functionality in some individuals with MS. Another showed that treatment with ginkgo biloba does not improve cognitive performance in people with MS. It’s important to note that ginkgo may interact with many different prescription medications so its use should be discussed with healthcare providers.

Echinacea is a flowering plant native to North America and a member of the daisy family. Some people believe that it is helpful for decreasing the duration and symptoms of the common cold, but there is no scientific evidence to support this effect. Echinacea appears to stimulate the immune system, by increasing the number of white blood cells (which fight infections). As mentioned earlier, boosting the immune system could theoretically worsen MS, therefore, echinacea is not recommended for people with the disease.

St. John’s Wort is a yellow flower that grows in many parts of the world. It is generally used as an antidepressant. This herb is generally well tolerated and has no known effect on the immune system that could be concerning to people with MS, however the herb has known drug interactions with many medications. There is a relatively high incidence of depression among people with MS and St. John’s Wort may be helpful in cases of mild depression. St. John’s Wort is not suitable for anyone with severe depression. It is important to recognize that depression should not be self-diagnosed or self-treated, and treatment with St. John’s Wort should be done only under a doctor’s supervision.

Valerian is a perennial flowering plant native to Europe and Asia. The medicinal part of the plant is its unpleasant-smelling root. Valerian is sometimes used as a sleep aid. People with MS may have difficulty sleeping, and difficulties with sleep may contribute to MS-related fatigue. Thus, a sleep aid may be very useful to some people with MS. Valerian is usually well tolerated. However, its effects on the immune system have not been studied. It’s important to note that valerian may have a lingering sedating effect, which may worsen fatigue in some cases. Also, valerian may increase the sedating effects of some prescription medications.

Asian ginseng is a plant that grows in Korea, northeastern China and far eastern Siberia. Its root has been used to make medicine in China for centuries. Ginseng’s many beneficial effects supposedly include boosting energy, lowering blood sugar and cholesterol levels, reducing stress, and promoting relaxation. While an herb that increases energy and strength would be of great use to people with MS who sometimes suffer from debilitating fatigue, there is insufficient data to support these benefits. Although some evidence suggests ginseng might reduce fatigue and have a significant positive effect on quality of life in people with MS, other studies raise the possibility that ginseng may stimulate the immune system in ways that may be detrimental to people with MS. Further studies are needed to conclude whether ginseng is safe or not, and to confirm any of its therapeutic effects.
Cranberries are grown in bogs in North America. As alluded to earlier, this herb is frequently used to prevent or treat urinary tract infections. There is an active ingredient in cranberries, proanthocyanidin, which can prevent adherence of bacteria to the bladder wall. Some, but not all, clinical trials of cranberry have shown that this herb prevents urinary tract infections. Bladder issues are common among people with MS and taking cranberry may be a helpful preventive measure. Increased fluid intake and improved hygiene may also be helpful in this regard. Cranberry has very few side effects and is reasonable for most. Cranberries should never be used to treat existing urinary tract infections. Urinary tract infections can have serious consequences for people with MS and often require antibiotic treatment from a physician.

Dietary supplements may be an attractive option for people with MS in their efforts to manage the disease and its symptoms. However, supplements can cause side effects or harm when taken in combination, at high doses, or when taken instead of prescribed medications. Supplements can also interact with certain prescription drugs in ways that might cause problems. Many contain active ingredients that can have strong effects in the body and the scientific evidence surrounding their benefits is inconclusive. Because supplements are not regulated in this country, being educated and careful about their use is very important. It’s important to let your health care providers know which supplements you’re taking, and which ones you are considering so you can discuss what’s best for your overall health.

Healing Meals Community Project – “Our Work is Heart Centered, Love Guided”

The Healing Meals Community Project (HMCP) is a nonprofit organization based in Bloomfield, CT, with a dual mission. They provide healthy, organic meals, free of charge for 14 weeks, to clients and their family members in and around the greater Hartford community who are undergoing treatment for serious illness. Their mission is to not only help clients logistically during a difficult time, but also to teach them through direct experience that organic, nutrient-rich food sustains and supports health. Youth volunteers, ages 14+, play a key role in each step of the process, including food procurement, preparation and packaging. They, too, learn the importance of eating healthy food. Volunteering at HMCP offers them a wealth of other valuable lessons, too, such as teamwork, leadership skills, and helping those in need. According to Sarah Leathers, founder of HMCP, “One could say HMCP is a youth development program that just happens to make beautiful, healthy meals for families in crisis.”
Sarah’s passion for community service and healthy eating clearly runs in the family. In 2007, her sister, Cathryn Couch, founded the Ceres Community Project (CCP), a nonprofit with an identical mission in California. The inspiration behind CCP came when Cathryn helped a high school girl cook and serve weekly meals to a family struggling with cancer. In Sarah’s words, “She knew that this was something special and she hasn’t stopped cooking since.” Cathryn also developed the Nourishing Connections Cookbook at that time. This useful book contains many of the recipes that Cathryn created for Ceres clients, as well as a wealth of information about the relationship between what we eat and our health. Since its inception, CCP has provided over 665,000 meals to 3,700 families in Sonoma County, CA. Today, it has 12 affiliates across the country and abroad, many founded by families that received CCP’s generosity and kindness, and wanted to pay it forward. HMCP is one of those affiliates. Sarah shares, “I had my own health crisis and knew the importance of feeding my body the best food to help my immune system. I watched what my sister had developed and knew how important that work was… I knew someday I would start my own organization.”

When asked about the importance of a healthy diet, Sarah explains, “When your body is compromised during a health crisis, there are so many things that you don’t have control over. One thing you can control is what you choose to put in your mouth. When you give yourself the cleanest, best nutrient-dense food, you’re giving your body love and nourishment that is healing. With all the toxins that go with treatment, whether it’s chemotherapy, radiation or other medications, your body is constantly fighting those medications and it’s looking for something pure and clean to help it fuel.”

Meals from HMCP are one hundred percent free of gluten, dairy, corn and soy. According to Sarah, “Those are some of the most common inflammatory foods that we know. We understand that not everyone can live 100% organic. We educate our clients on the dirty dozen and the clean fifteen. The dirty dozen are the known produce you should stay away from because they’re known to have the most pesticides on them. When you’re more educated, you can make better choices. We talk to people about eating seasonally. For us in Connecticut, our local food sometimes comes from hundreds of miles away this time of year. If you’re eating seasonally, you have a better opportunity to have it come from a closer place. During growing season, we get our produce from a local organic farm, Holcomb Farm in Granby, CT. It is picked on Tuesday and we are cooking it on Wednesday. It doesn’t get better than that. To be able to take something that’s picked the day before, cook it and get it to our clients the next day, that’s really important.”

HMCP provides healthy meals not just to the person that is sick, rather to their whole family. Sarah explains why, “Whether it’s the client or the family, they’re all in crisis. The spouse or child of someone that is sick is busy caring for the other person, they can’t show that they’re stressed or in crisis. It’s so easy for that family to go down this unhealthy road because all they can think about is everything else they’ve got going on. It’s easy to
swing by and pick up a pizza, or a casserole of macaroni and cheese, but that’s not going to help sustain them as well during the stress they’re going through. We believe in it. We hear it from our clients. We live that way.”

Since its inception in 2016, HMCP has had over 500 volunteers help them in their mission, 275 of which have been youth from surrounding towns. On any given week 45-50 volunteers help with a wide variety of activities, from shopping to preparing and delivering meals. With the understanding that family and school come first, youth volunteers are asked to make a 3-month commitment to work alongside adult volunteers. After 50 hours of service, youth volunteers earn their blue apron. After 100 hours of service they earn their chef coat. In the coming year, two youth volunteers will be invited to join HMCP’s Board of Directors. When asked about involving teenagers and young adults in their program, Sarah states, “With regards to the youth piece, we truly have a dual mission… When we start a shift, the kids come in. Their cell phones go in a shoe pocket. They grab their nametag, put on their apron and we come together in a circle before we start. We take a moment to really ground everybody, and then we honor our clients. We read every name of the clients we’re serving that week, so there’s an opportunity for all of us to think about them during the time that we’re cooking or packaging their meals. All of our youth take time out of their shift to write a personal note to a client. It’s amazing to go over and be with the kids when they’re writing notes and look at the care that goes in to them. Sometimes, these are sixteen-year-old boys who are drawing pictures and writing beautiful notes in hope that they will bring a smile to somebody’s face. It’s a moment for all of us. I try to go in the kitchen regularly because it fuels my soul. It allows me to take a moment and grounds me in what I’m doing.”

The HMCP team is comprised of ten hard working individuals. Sarah is the only full-time staff person. In her words, “I have an amazing team. My staff dropped out of heaven. Truly they are such a gift. I tell my volunteers and staff all the time that the energy they carry out into the world about what they do at Healing Meals is going to be what moves us forward. It’s just been this amazing gift of our community at large believing in us.”

HMCP clients and their families have free meals delivered right to their doorstep for 14 weeks. In Sarah’s words, “You can’t change somebody’s way of eating in a week or two. Our long-term goal is to get people to think differently about the food choices they make.” Every week clients and their families receive a chicken dish, a fish dish, two vegetarian dishes and a hearty soup. In addition, every client (who is ill) gets a quart of immune broth consisting of organic vegetables with adaptogenic herbs (known for building the immune system). According to Sarah, “Every week, it’s so important for the color, texture, and spices to be different. When somebody is in a health crisis, many times they’re not interested in eating at all, but if they go to the refrigerator and they see our beautiful sunny beet and carrot burger with beautiful purple and orange color and a side of kale, it looks beautiful.” HMCP services are currently offered to clients and their families in 43 towns around the greater Hartford
area that are experiencing a health crisis and not receiving hospice care. Sarah states, “We’re at capacity right now, cooking and packaging one day a week. In 3 hours on a Wednesday, we cook over 400 meals.” Anyone interested in receiving meals can call Healing Meals Community Project at (860) 431-0507 or email Emily Safino for more details.

There are many ways to support this powerful mission. One fun way that brings family and friends together is a Nourishing Our Neighbors Dinner Party. Sarah explains, “I wanted an opportunity to bring people around the table. My mother was a fabulous cook and she loved to entertain. My dad was in sales and frequently brought clients to the house. We were always sitting around the dinner table with clients and friends. I remember that as such a wonderful opportunity to meet people and hear their stories. So, I came up with this idea to do these dinner parties as a fundraiser… We go to someone’s house and provide a four course organic meal that is cooked and presented by our youth. They provide the table and friends to share the meal. Our youth share about HMCP and why they’re involved. It’s an opportunity for those who know us to share with their friends. It has been an amazing opportunity for us. Our youth have an opportunity to really shine and take on a leadership role, to get up in front of people and talk. I’m always blown away when I hear them introduce themselves, and talk about why they’re involved. It truly comes from their heart, and it’s different every time.”

HMCP has exciting initiatives planned for the future. According to Sarah, “Our focus in 2019 is how to educate the larger community. We’re doing eight community dinners working with Cigna, which is really exciting… We’ve just launched a partnership with Whole Foods. The three Connecticut stores, two in West Hartford and one in Glastonbury, are now selling five of our recipes. Whole Foods is making, packaging and selling the recipes, and a dollar for every pound sold will benefit HMCP… We’re also planning to do small cooking classes for clients and their families, through a grant from the Love of Amy Foundation. We’ll be bringing a couple of families together, cooking with them, helping them to see how easy it is to cook healthy and then sitting down at the table together.”

HMCP also has a small organic garden that they hope to expand in the coming year. Sarah states, “The Connecticut Valley Garden Club will be working alongside our youth this spring, summer and fall to grow our own organic garden. The kids will be able to plant, pick, weed, bring it into the kitchen, cook it, package it and out it goes. They’ll be able to say all of it is from us.”

When asked what she enjoys most about HMCP, Sarah shares, “I love receiving a note of gratitude from a client and sharing it with our youth so they can see that they have a profound impact in the lives of those in our community. I love watching a young person come into our community for the first time, nervous, unsure about where they fit in the puzzle, and seeing the other youth welcome them openly. By the end of the shift they have new friends. I love the energy and the culture we have created.” When asked what her biggest challenge has been, she states, “We have grown so quickly and have many organizations that want to align with us and we are learning to evaluate what makes sense for our organization.”
Sarah’s daughter, Samantha, was diagnosed with MS two years ago. This news rocked their family. Reflecting on this difficult time, Sarah shares, “There was definitely denial at first… We immediately changed her diet, removing the most inflammatory foods. When she had her second flare up we had her do a FIT test which revealed her intolerance to a number of foods that she was eating on a regular basis that were causing inflammation… She is nothing but amazing and courageous. Samantha sees the good, always the good, and puts that out to the world every day… I don’t try and tell Sam how to feel about her diagnosis but I do remind her that she has a supportive family, and don’t focus on the diagnosis. Try not to let it fill your head with what could be, instead be present and grateful for today.”

The good work that HMCP does has a ripple effect, not only in the lives of the clients they serve, but also in the lives of their youth volunteers. Their clients and their families receive nourishment for the body and soul, and their youth volunteers learn lessons that go far beyond food preparation and delivery. Their eyes are opened to their neighbors in need and compassion for them is fostered. Reflecting on her remarkable journey with HMCP, Sarah shares, “At this point in my life, to be able to wake up every day and be excited about what I’m doing is such a gift. It’s a labor of love. There are many late nights and long, long days, but I don’t feel like that. I feel like this is such a gift I’ve been given and my role is to shepherd this out and get everybody who works and volunteers alongside me to feel that same thing.”

Unwell Adventures – “The Power of Social Media for Good”

An MS diagnosis brings with it a wide range of powerful emotions. Some may feel angry, teary or afraid. Others may feel relieved, especially if they’ve spent months, or even years, trying to understand the reason for their symptoms. If MS manifests itself suddenly and a diagnosis is made quickly, one may feel shocked. Others may feel like it’s unreal, happening to someone else, or even a lack of emotion.

Samantha Leathers was diagnosed with MS in 2017, at the age of 27, 3 months after she got married. She had just lost one of her best friends to terminal brain cancer. Samantha started having numbness and tingling in her hand and thought it was carpal tunnel syndrome. The day her friend passed away, her whole left side went numb. Samantha thought she was having a physical reaction to grief. She went to a walk-in
Samantha has a great passion for travel and new adventures. In her words, “Travel has been a big part of my life. It’s a part of my identity and who I am. It’s more than just travel, it’s about experiencing new things and trying new activities. That’s what keeps my blood flowing.”

One of the most meaningful places she visited was Ghana, West Africa. Samantha took a break from college to volunteer at an orphanage there on and off for two years. When asked to describe this experience and the influence it had on her life, Samantha said, “The situation there was very remote and it was pretty dire. It was a crazy experience that’s really created and reinforced who I am. It’s put me on a path to where I am.” Samantha and her husband look forward to their next big adventure in the spring, a trip to Tel Aviv and Petra.

Seven months ago, Samantha decided she wanted to share her MS journey with others who may be struggling in the same circumstance. She started her Instagram account, called Unwell Adventures. She began by posting stories describing her first year when she was experiencing MS flares, as well as things that were helpful during that difficult time. Samantha shares, “I didn’t start it when I was diagnosed, I waited a year because I was scared. I went through a time when I didn’t tell a lot of people. My emotions were at the brim. I was in survival mode. Once I started to be more open I realized how great that was... When you’re told you have MS, your first thought is that you’re going to be in a wheelchair. People who are newly diagnosed don’t hear about the people who are doing well and it feels like this terminal diagnosis. There are so many people who manage and all of those stories get lost... My husband and I went to Thailand and Cambodia last year. People looked at the pictures and said, ‘You don’t look sick.’ They didn’t see the fact that I was having my biggest flare up while I was there. I could barely walk. I used Instagram to shed light on the fact that I was there, it was beautiful, but I was crawling up the side of a temple. It’s one of those moments that I had to laugh because it was ridiculous, but I don’t want to miss out on life. That was a very powerful moment.” Samantha uses Unwell Adventures to share snippets, or stories, from her daily life. She explains, “I typically share the days I have infusions because that’s a really vulnerable time for me. I try and make it light hearted, because that’s just who I am. I try to be as authentic as possible.” Samantha also shares deeper moments on her
In her words, “These are the things I really want to have a deeper discussion about. For example, talking about how I’m feeling, or I went mountain biking for the first time. Putting a caption to it that I tried this new activity and it made me feel alive. I want that to really live there as that message.”

Today, Unwell Adventures has almost 400 followers, both with and without MS. Samantha not only offers support to others, but has also found it to be a great source of encouragement herself. She shares, “No matter how amazing your support system is, they won’t ever be able to really understand. My husband is amazing, my parents and the rest of my family are amazing. They support me. I could not be more grateful. At the end of the day, they don’t know what it feels like. I’ve found support and connection through Unwell Adventures. This is the power of social media for good.” When Samantha went to her first MS event, it was an overwhelming experience. In her words, “I had an absolute breakdown, which I didn’t expect. I contacted one of my MS buddies and she understood. That’s an amazing gift I wouldn’t have had if it weren’t for Unwell Adventures… The engagement has been really incredible. I’ve also been able to connect with people who have other autoimmune diseases. Because the feelings of fear, the lack of control, all of those emotions go with anything. Being able to talk about taking back some control, whether it be diet or fitness, has really translated with a lot of other people as well as the MS community.”

Samantha’s mission for Unwell Adventures is multifaceted. She explains, “I want to give a voice to a generation of MSers in their late 20’s, of which there is a very large population, and provide more relatable resources for families, for people going through it.” Samantha hopes that Unwell Adventures will also help to invoke people’s resilience. In her words, “Resilient is now a word that I love deeply. I’m not necessarily working toward a cure because right now there isn’t one. I’m working to live my life with this disease forever. There’s this sense of resiliency and strength in so many people I’ve met with MS, it’s been so humbling. I just hope to continue to propel that.”

Anyone interested in following Unwell Adventures must download the Instagram App from the App store or Google Play. Unwell Adventures can be found by searching for it by name within the App, or other MS-related hash tags, such as #ms, #strongerthansms, or #themssociety. For those curious how it got its name, Samantha shares, “Some think ‘unwell’ has a negative connotation. I think it’s kind of sarcastic, it’s sassy which is kind of ‘me’. It’s perfect. It’s like that moment in Cambodia when I thought my life was exploding, but it was also kind of an adventure and I still wanted to live it. I played around with all of these positive names and they were beautiful, but they just didn’t really seem to fit. I wanted to show the imperfect struggle and share that vulnerability of life.”

When asked what she enjoys most about Unwell Adventures, Samantha states, “The support and reinforcement that I’ve gotten. Being able to connect with people who I feel like I can really make a difference with, and vice versa. It really feels like I’m doing what I’m supposed to be doing.” When asked what her biggest challenge has been, she shares, “Being as vulnerable as I feel like I should be.” When asked if she
has a message she would like to share with others recently diagnosed with MS, Samantha replies, “I would say just try to stay positive. It is so overwhelming at first because you’re scared, you’re trying to take care of yourself, and you don’t know what’s going on. Looking back, it was such an emotional time… Remember you are not alone, share with people. Don’t keep it in. Obviously you don’t have to tell everybody, but lean on your resources because they also want to be there for you… You’re going to get through it. You’re going to figure it out.”

Samantha is a Brand Marketing manager for an organic granola company. She is also a student at the Institute for Integrative Nutrition, working toward getting her health-coaching certificate. In the future, she would like to start doing health and lifestyle coaching through Unwell Adventures, sharing the importance of fitness, exercise and maintaining a routine with others living with MS. If you haven’t already done so, consider following Unwell Adventures today. Whether you have MS or not, Samantha’s positive, can-do attitude is infectious and is sure to add a ray of sunshine to your day.

Repository Spotlight - Dr. Robert Clark, University of Connecticut School of Medicine

Researchers at the University of Connecticut School of Medicine believe that a normal exposure to small amounts of bacterial products may be lacking in people with MS. Lipid 654 is a lipid/peptide-based molecule that is produced by bacteria commonly found in the mouth and gastrointestinal tract. Because lipid 654 levels are significantly lower in people with MS, it is a known biomarker for the disease that is associated with the microbiome. This change in microbiome, in turn, causes the abnormal response of immune cells in people living with the disease. Dr. Clark and his team used ACP
Repository samples to compare bacterial product levels, such as Lipid 654, in people with MS versus healthy controls. The expected lower level of bacterial products in people with MS, as well as the predicted altered immune cell responses, may lead to a greater understanding of the causes of MS and may also represent new therapeutic targets. Dr. Clark’s study is just one of more than one hundred studies using ACP Repository samples to advance and accelerate research into MS.

**iConquerMS™ Spotlight – Wellness and diet strategies used by REAL MS participants**

**REAL MS™** (Research Engagement About Life with MS) is an ongoing study of MS launched by ACP through the iConquerMS™ initiative two years ago. Study participants periodically complete questionnaires about their MS experience through the iConquerMS portal. In 2017 we began asking REAL MS participants which vitamins, minerals and supplements they were taking, and if they found them helpful in managing their MS and improving other aspects of their life. Data collected to date reveal some interesting differences between the most popular and the most helpful options. For example, the most popular diet choices among study participants were eating organic and gluten-free foods. While it was one of the least popular, the Swank diet was reported by participants who had tried it as the most helpful, followed by eating gluten-free. The most frequently used supplement overall was Vitamin D, with 59% of respondents indicating they found it helpful. The second most popular supplement was a multivitamin, which participants reported provided an almost equal benefit. The supplement reported as most helpful, however, was iron, benefiting 61% of respondents, followed by magnesium and vitamin C. With regards to herbal supplements, the most commonly used was turmeric, and the one reported to be most helpful was marijuana, followed by cranberry. Data like these are a growing and powerful resource for MS research, providing investigators and clinicians with real-life information on what living with MS is like. If you haven’t already done so, please join iConquerMS today and add your voice to those already helping to steer the future direction of MS research!