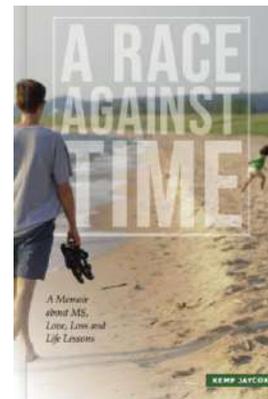


# November 2023 Newsletter



## A Race Against Time

Volunteers make a huge difference in ACP’s ability to accelerate and advance MS research. They help us in a variety of roles, from office work to fundraising. Kemp Jaycox has organized many fundraising events in support of ACP over the past two decades, raising close to \$60,000. He recently published his memoir, “A Race Against Time,” and is donating part of the proceeds to ACP. Kemp hopes that his life story can inspire others to find resilience and purpose to help face any challenges they may encounter.



*Kate, Kemp and Cindy on Cape Cod*

Kemp grew up in Cincinnati and currently lives in Cleveland with his wife, Cindy, and his 16-year-old daughter, Kate. He has Bachelor’s degree in Biological Sciences and a Master’s degree in Environmental Science. He spent the first half of his career doing environmental consulting and worked on renewable energy and sustainability projects that help address climate change for the second half.

An important part of Kemp's life is being a member of [Forest Hill Church, Presbyterian](#) in Cleveland Heights where he enjoys volunteering, when able. One of his volunteer roles was co-teaching a class about reconnecting with nature. This experience inspired him to establish the Kemp Jaycox Environmental Sustainability Fund to help the church operate in a more eco-friendly and sustainable manner.



“Our church is an amazing support network for me. I feel blessed that so many people there love me and will do anything to help me and my family.”

As part of a guest sermon that he gave in 2015, Kemp said, “Have faith and know that most clouds have a silver lining and most dark times will be followed by brighter periods of time... Many days are a struggle, and I don't know how this will play out. Actually, none of us knows what our future holds! My challenge – and what I hope you can do – is to find meaning in the suffering. Have faith; know that God is always present; and enjoy life as much as possible.”



Kemp has been living with MS since 2003. In his words, “I have wrestled with this disease from the onset, and I have felt robbed that it hit me in the prime of my life. I was in great shape in my late 20s when I was running, playing basketball and tennis and competing in triathlons. I was healthy and happy. Today I am 50 years old, retired due to my disability and struggling to maintain every bit of strength and function that I can to maintain as normal a life as possible.” Despite his physical challenges, Kemp is grateful that MS has not affected him cognitively too much, so he is able to stay engaged mentally and socially and he is able to take on tasks like writing his memoir.

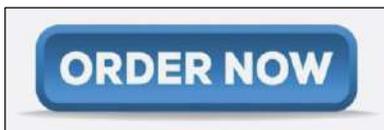
Kemp's book is a legacy for his daughter, Kate. In his words, “I wrote this memoir so that Kate can one day enjoy reading more about my life. The more I wrote, the more I realized other people could benefit from hearing my story.” Kemp's story is rooted in his MS journey, and also in tragic deaths and profound grief experienced in his formative years. The words in the



*Kemp and his daughter, Kate*

beginning pages of his memoir sum it up perfectly, “Kemp’s story is at once heartbreaking and comical. It is tragic and joyful. It is proof that each of us leads a life precious and fragile.” When asked what he enjoyed most about writing his memoir, Kemp shares, “I enjoyed looking back on the various stages of my life and writing about them. Despite the significant losses I’ve had and continue to experience, writing the memoir has helped remind me that I still am very blessed. When I am really struggling, I try to remind myself of some of these blessings. The most important message I hope to convey to readers is to persevere and enjoy your life the best you can despite your challenges and circumstances.”

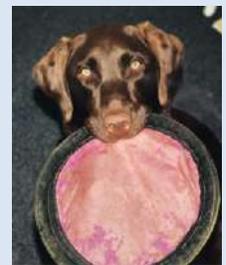
Kemp lost his sister and his father to suicide in his late teens and early twenties, respectively. He shares, “I learned a lot about bravery, courage, survivorship and resilience at a relatively young age – traits and skills that have served me throughout my life.”



Interested in reading Kemp’s inspiring story? Looking for the perfect gift for a loved one this Christmas? You can order your copy of “A Race Against Time” today! Click [here](#) for a copy with color photos and [here](#) for a copy with black and white photos. All proceeds will be donated to ACP and the Kemp Jaycox Environmental Sustainability Fund at Forest Hill Church.

Kemp has organized many fundraising events in support of ACP over the years. When asked about the inspiration behind his generosity, Kemp responded, “MS is such a complex disease with so many unknowns including different causes. I strongly believe that research is how collectively scientists and patients will help figure out what causes this devastating disease as well as a cure. I have always been drawn to ACP for their focus on facilitating research to determine the causes of this awful disease. This is my

“When Cindy and I lived in Cincinnati, we started a small group to organize fundraising events for ACP, called the [Cincinnati Cure Project](#) (this was when ACP was known as the Boston Cure Project). Our favorite event was the K9 Happy Hour, where people brought their dogs to a dog park, had drinks, socialized and bid on silent auction items. These events were a lot of work to organize but they were a great deal of fun!”





each other and continue to love and support each other. We have started writing the book and hope to find an agent who will connect us with a publisher (if you know of any literary agents, please [let us know](#)). We think the book will be a useful resource for any couple dealing with a chronic disease. Stay tuned!”

## Can Dietary Supplements Help MS?

iConquerMS members provide information about wellness interventions they have tried on their [REAL MS surveys](#). These data are a valuable resource for researchers as they seek to learn more about their safety and effectiveness in people with MS. Many turn to dietary supplements to help with their symptoms and feel better. Listed below are some vitamins, minerals and herbs that are of interest in MS.



## Vitamins

Vitamins are [organic](#) compounds that are essential for normal growth and nutrition.



---

### Vitamin A



Vitamin A is important for maintaining healthy vision and proper function of the immune system, among other things.

[Research](#) shows vitamin A does not play a role in the disease course of relapsing remitting MS.

A [recent study](#) found vitamin A supplementation in people with acute optic neuritis in MS could lessen optic nerve loss.

---

### Vitamin B6



Vitamin B6, also known as pyridoxine, helps to maintain a healthy metabolism, as well as healthy skin and eyes. It also supports nerve and liver function.

According to a [2020 study](#), vitamin B6 decreases inflammation (which plays a significant role in the MS disease process).

[Researchers](#) in Iran suggest that a higher dietary intake of vitamin B6 improved cognitive function in Neuromyelitis Optica (a related autoimmune disease).

---

## Vitamin B12

Vitamin B12, or cobalamin, is key to normal brain and nervous system function. It is also involved in the production of red blood cells and DNA.



[Research](#) suggests that MS is associated with vitamin B12 deficiency, however further study is needed to fully understand this relationship.

A [2019 study](#) found that vitamin B12 and folic acid supplementation improves quality of life in people with MS.

---

---

## Vitamin C

Vitamin C is necessary for the growth, development and repair of all body tissues. It's involved in many body functions, including the immune system.



[Research](#) shows that vitamin C helps treat neurological disorders like MS in animal models, but further study is needed to confirm this benefit in humans.

According to a [recent review](#), vitamin C supplementation does not reduce the risk of MS in humans, and can be potentially harmful.

---

---

## Vitamin D

Vitamin D is essential for bone strength and may support the immune system and other functions.



[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.

On the other hand, a [2023 clinical trial](#) concluded that high-dose vitamin D3 supplementation in people with RRMS may not be beneficial.

---

---

## Vitamin E

Vitamin E plays many important roles in the body, including helping to keep the immune system strong against viruses and bacteria.



[Researchers](#) in Brazil found that treatment with vitamin E and ebselen (an antioxidant) protects against demyelination in animal models of MS.

According to [Norwegian researchers](#), vitamin E supplementation decreases the odds of new lesions in RRMS patients taking interferons.

---

## Minerals

Minerals are [inorganic](#) nutrients. Macrominerals are required by the body in large amounts. Those needed in small amounts are called trace minerals.



## Selenium



Selenium is a trace mineral that has antioxidant effects, and it also plays an essential role in the production of thyroid hormone.

A [2020 study](#) suggests an organic form of selenium reduces central nervous system inflammation and clinical disease severity in a mouse model of MS.

[Research](#) suggests that selenium levels may be lower in people with MS, however it is unclear whether selenium supplementation would help.

## Calcium



Calcium plays a key role in the formation of teeth and bone, muscle contraction, the release of hormones and transmission of nerve signals.

[Investigators](#) in Poland found that calcium metabolism is disrupted in relapsing remitting MS and this effect increases during disease progression.

People with MS are at increased risk for bone loss (osteoporosis), so adequate calcium intake is crucial.

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.”



## Zinc



Zinc plays a key role in a healthy immune system, cell division and growth, wound healing, carbohydrate metabolism and the senses of smell and taste.

A [recent study](#) in mice found that zinc is involved in spinal cord demyelination and motor deficits. More research needed to confirm these effects in humans.

There is [evidence](#) that zinc levels are lower in people with MS and this effect is even more pronounced in those taking disease modifying therapy.

## Herbs

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.



---

### Ginkgo Biloba



Ginkgo Biloba is an antioxidant. It also inhibits [platelet activating factor](#), which causes decreased activity of certain immune cells.

---

Research into its therapeutic benefit has had mixed results. One [study](#) found it helps with fatigue, symptom severity and function in some people with MS.

---

Another [study](#) showed that treatment with ginkgo biloba does not improve cognitive performance in people with MS.

---

---

### Echinacea



Echinacea is a flowering plant native to North America and a member of the daisy family.

---

Echinacea is not recommended for people with MS because it stimulates the immune system.

---

According to a [recent study](#), herbal supplements containing echinacea may interfere with corticosteroids.

---

---

### St. John's Wort



St. John's wort is a yellow flower that grows in many parts of the world. It is generally used as an antidepressant.

---

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.

---

This herb is generally well tolerated and it doesn't affect the immune system. It does, however, have known drug interactions with many medications.

---

---

## Valerian



Valerian is a perennial flowering plant that is sometimes used as a sleep aid. The medicinal part of the plant is its unpleasant-smelling root.

---

A [2018 study](#) suggests valerian improves sleep quality in people with MS, so it can be considered a complementary therapy for those with sleep disorders.

---

Valerian is usually well tolerated, but its effects on the immune system have not been studied.

---

---

## Asian Ginseng



The potential benefits of Asian Ginseng include boosting energy, lowering blood sugar and cholesterol levels, reducing stress and promoting relaxation.

---

Research into its benefit in people with MS is mixed. One [study](#) suggests it may reduce fatigue and significantly improve quality of life in people with MS.

---

Other [research](#) raises the possibility that ginseng may stimulate the immune system in ways that may be detrimental to people with MS.

---

---

## Cranberry



Cranberry is often used to prevent urinary tract infections (UTIs). It should never be used to treat an existing one.

---

A [2014 study](#) concluded that taking cranberry extract twice a day did not prevent UTI occurrence in MS patients with urinary disorders.

---

[Research](#) shows that juice or whole cranberries may be more effective than supplements at preventing UTIs in MS patients with neurogenic bladder.

---

## General cautions about dietary supplements



**They are not evaluated by the FDA, which means...**

- Their labels can't make claims about being able to treat or cure any illness
- Manufacturers are not required to prove their effectiveness or accurately report what they contain
- Supplements may vary widely in both the amount and quality of their ingredients

Dietary supplements may seem appealing for people with MS trying to manage the condition and its symptoms. However, it's essential to exercise caution when using them, as they can lead to side effects or harm, especially when combined, taken in high amounts, or used instead of prescribed medications. Supplements can also interact with certain prescription drugs, potentially causing issues. Many supplements contain strong ingredients, and their benefits are not clear. Since supplements aren't regulated, it's important to be cautious. Tell your healthcare providers about the supplements you're using or thinking about using, so you can make the best decisions for your health. Want to help us better understand the benefits that dietary supplements may hold for people with MS? If you haven't already, please consider [joining](#) iConquerMS and start contributing to MS research today!

**DID YOU KNOW?**  
about MS  
research

Accelerated  
**Cure**  
project  
for Multiple  
Sclerosis

**Multiple sclerosis research is not limited to only drug trials.**

There are many ways for people living with MS to contribute to research studies without taking or changing medication. For instance, you can participate in studies that observe symptoms or take surveys on topics such as quality of life.

For more information on current and past MS-focused research projects, visit [www.iConquerMS.org/research-projects](http://www.iConquerMS.org/research-projects).

iConquerMS™

## November 2023 Donor's Corner

How do your [donations](#) accelerate research for a cure and improve the lives of people affected by MS?

Your generosity supports ACP's initiatives to accelerate MS research for quicker diagnosis, more effective treatments, and a cure for all living with the disease.



ACP Repository

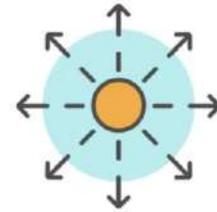


iConquerMS



Inclusive Engagement  
in MS Research

This month, we're highlighting how your generosity enables ACP and our iConquerMS network to disseminate research results in actionable and understandable ways.



The [Chat with Chat webinar series](#) is an ACP/iConquerMS program that brings the latest in MS research to you! Hosted by our research collaborator Chat Ngorsuraches, these conversations provide a glimpse at the researchers working with iConquerMS, what they study, and how their work will benefit people with MS.



[Investigators](#) at the University of Melbourne (Australia) analyzed data from the [REAL MS Wellness & Diet survey](#) to understand how health and well-being for people with MS are affected by various diet and wellness practices, including vitamin D and omega-3 supplement use.



Chat with Chat  
Hosted by *Surachat Ngorsuraches*

iConquerMS

Episode 9

**"Assessing the impact of lifestyle behaviors on health outcomes in people with MS"**



Featuring

Featuring  
**Nupur Nag, PhD**  
| The University of Melbourne, Australia

[Chat with Chat Webinar Episode 9](#) features an interview with Dr. Nupur Nag from the University of Melbourne. Details about this and other projects, including research results, can also be found on the new [Research Projects page](#) of the iConquerMS website!

Thanks to your support, ACP and iConquerMS are able to spread the word about current MS research findings and other MS-related topics. We enable people affected by MS to use the most up-to-date information to inform their healthcare decisions in collaboration with their healthcare providers. Join our team and consider making a [donation](#) today! Together, we are working to improve the health and quality of life for everyone in the MS community.



## November 2023 iConquerMS Spotlight

In the summer of 2016, iConquerMS launched [REAL MS](#) (Research Engagement About Life with MS), a longitudinal study of MS. Network members complete detailed questionnaires online twice each year on a variety of subjects, including health history, diet, exercise and their experience with MS. The information collected through these surveys will play a pivotal role in helping scientists and clinicians gain a better understanding of the health and quality of life over time for people with MS.



Talk with your doctor before starting any new therapy. It's important to keep him or her informed about what you take (or what is done) and any changes you experience.

In 2017 we began asking REAL MS participants which dietary supplements they were taking, and if they found them helpful in managing their MS and improving other aspects of their life. Data collected reveal some interesting differences between the most popular and the most helpful options.

Which supplements are the most popular? Which are the most helpful?

# AND THE SURVEY SAYS...

## Diets

- The most popular diets among REAL MS participants were eating organic and gluten-free foods.
- While it was one of the least popular, the [Swank diet](#) was the most helpful, followed by eating gluten-free.

## Vitamins

- The most popular supplement was vitamin D, followed by a multivitamin (59% of respondents found either option helpful).
- The most helpful supplement was iron (benefitting 61% of respondents), followed by magnesium and vitamin C

## Herbs

- The most popular herbal supplement was turmeric.
- The most helpful herbal supplement 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.



iConquerMS brings together people with MS, their care partners, researchers and others to understand MS and search for solutions. If you haven't already, please consider [joining](#) today!

## November 2023 Research Spotlight

# RESEARCH OPPORTUNITIES

Research opportunity information may be provided on behalf of an external organization. Please refer to the contact information within each listing to identify the contact for questions or comments.

### Table of Contents

#### Research Opportunities

Page 1

MS Caregiver Survey

Page 2

Colorado State Hormone Study

Page 3

BIPAMS Cognitive Health Study

Page 4

TEAAMS Exercise Study

Page 5

University of Iowa Diet Study

Page 7

Our Questions Have Power



### Calling All MS Caregivers!

ACP is working with a small group of MS caregivers and MS professionals (Jon Strum of RealTalk MS, Rosalind Kalb of CanDo MS, and Deborah Miller of the Cleveland Clinic) to develop a “Caregiver Protocol.” The Protocol will be an online compilation of resources to support MS caregivers at all stages of the caregiver journey. We’ve developed a [short survey](#) to gather the perspectives of MS caregivers so that their insights can help shape the Protocol. Your input is valuable and much appreciated! Thank you!

---



## **Hormonal Stages of Life and MS**

Researchers at Colorado State University are conducting a survey study that aims to determine whether distinct hormonal stages of life (menstrual cycle, hormonal contraception, pregnancy, postpartum, post-menopause) influence disease symptomology, physical function, and the capacity to perform activities of daily living in women living with MS.

Participation involves filling out an online questionnaire that will take approximately 10-15 minutes to complete. This is an anonymous questionnaire in which no personally identifiable information will be collected.

### **Inclusion Criteria:**

- Female sex assigned at birth.
- A diagnosis of MS.
- Aged 18 years or older.

**Survey Link:** [A Survey on the Influence of Hormonal Stages of Life on Multiple Sclerosis Symptomology and Physical Function](#)

If you have any questions about the research, please contact Kristin Johnson, Postdoctoral Research Fellow, at [kristin.johnson@colostate.edu](mailto:kristin.johnson@colostate.edu) or Brett Fling, Associate Professor and Director of the Sensorimotor Neuroimaging Lab, at [brett.fling@colostate.edu](mailto:brett.fling@colostate.edu).

For information about the impact of MS in women please see:  
<https://www.nationalmssociety.org/What-is-MS/Who-Gets-MS/Women-with-MS>

STUDY2022-0084-MOD006  
Effective: 8/11/2023  
UIC Office for the Protection of Research Subjects

# Research Opportunity

**Researchers at the University of Illinois Chicago (UIC)  
Invite You to Participate in a Voluntary Research Study**

**This is a nationwide, remote study that is examining the effects of two Internet-delivered programs for improving cognitive health among people with MS.**

**All participants in this study will complete online questionnaires, virtual cognitive and mobility testing, and wear an accelerometer. An accelerometer is a small device that measures physical activity by measuring steps/day.**

**The entire study can be conducted at home as no in-person visits are needed. Also, currently physically inactive refers to those who are not doing enough physical activity.**

**Participation in the study will last 12 months and participants will receive \$50 in compensation via gift cards for completing the 3 measures for a total of \$150.**

## Initial eligibility

- **Diagnosis of multiple sclerosis (MS)**
- **18 years of age or older**
- **Internet and email access**
- **Currently physically inactive**
- **Able to walk without assistance**

**For More Information:  
Contact the Project Coordinator**

**Key Words: BIPAMS-Cognition**

**Phone: (833) 329-1441**

**Email: [bipamscognition@uic.edu](mailto:bipamscognition@uic.edu)**

**Website:**

**<https://bipamscognition.ahs.uic.edu>**



**Behavioral Intervention for Physical Activity  
in Multiple Sclerosis - Cognition**



# RESEARCH OPPORTUNITY AT HOME EXERCISE STUDY

This study involves the **remote-delivery** of 16-week exercise training program for African-Americans with Multiple Sclerosis (MS)

## Benefits

- Contribute to ongoing research on African-Americans with multiple sclerosis (MS)
- Learn about methods of improving your health and well-being
- Complete an evidence-based, tailored exercise program in your home or community



## Eligibility

- Diagnosis of MS
- Self-identify as African American or Black
- Living in the Southeastern United States
- 18-64 years of age
- Internet and email access

**Contact us for  
more information**

(833) 727-1887  
enrl@uic.edu  
Keyword: TEAAMS



You are invited to participate in a research study comparing the effects of three diets – the modified Paleolithic diet (elimination of gluten, dairy, and eggs), a Time Restricted Olive Oil-based Ketogenic diet, or your usual diet with information about the USDA Dietary Guidelines for Americans. Participants in the usual diet group will be encouraged but not required to follow the

Dietary Guidelines for Americans diet. Quality of life, fatigue, mood, and disease activity will be assessed by online surveys, study participant tasks, & brain imaging. The study will be held at the University of Iowa Hospitals & Clinics over two years. It will consist of three visits to Iowa City, month 0, month 3, & month 24. Each visit can last approximately three and up to six hours.

### What you will be asked to do at home while on your assigned study diet

- Follow one of the three study diets randomly assigned to you for 24 months
- Report changes in health and medications
- Eat more non-starchy vegetables
- Eat more home-cooked meals
- Take recommended dietary supplements
- Complete daily food logs (three questions) on a smart phone
- If you are assigned to the ketogenic diet, you must take a blood ketone measurement daily for the first month and then twice a week for the rest of the study
- Complete online surveys
- Watch videos, review study diet guides and meet via Zoom to learn your assigned study diet
- Attend optional online support groups

### What you will be asked to do at each of three visits to UIHC

- Complete fasting blood draws
- Complete physical motor skills, cognitive assessment and visual function tasks
- Receive a non-contrast MRI brain scan at first and final end of study UIHC visit (Month 0 and 24)

### Requirements to participate

- Diagnosis of relapsing remitting multiple sclerosis (RRMS)
- 18-70 years old
- Able to walk 25 feet without support or unilateral support
- Willingness to adopt any of the three study diets, including the control diet
- Willingness to share medical records for the two years of the study
- Do not have heart disease, liver disease, kidney disease, or type 1 diabetes
- Do not have serious psychiatric disease that would make adopting a study diet more difficult
- Are not taking insulin or coumadin
- Have a smart phone, tablet or iPad to download a free app
- Have access to high-speed internet and a computer or smart phone to participate in video conferences via Zoom and complete online patient surveys
- Commitment to completing surveys for two years and attend the of end of study visit

## COMMON QUESTIONS

### Do I need to live within a specific mile radius of Iowa City?

No, however, if travel funds are needed, we may be able help. We can offer a travel stipend to support some travel expenses to and from Iowa City. Please speak with us about your needs. We also offer stipends to participants for attending the site visits and for completing the required online surveys.

### Can I pick the diet I want to follow?

We ask that you follow the diet assigned to you. If following your assigned diet becomes difficult contact the study team for assistance.

### Can I be in the study if I am in another MS-related study?

If you are in an interventional study investigating drugs, exercise, or other wellness behaviors you cannot be in this study. If you are in an observation-only study, you can still be in this study if you are willing to follow any of the three diets.

If you're interested in taking our screening survey, please visit the link below or scan the QR code with your phone:

→ <https://redcap.icts.uiowa.edu/redcap/surveys/?s=JX73EYRJNPF9MHRR>



If you have questions, please contact us at → [MSDietStudy@healthcare.uiowa.edu](mailto:MSDietStudy@healthcare.uiowa.edu)

→ [wahls.lab.uiowa.edu/join-study](https://wahls.lab.uiowa.edu/join-study)



Changing Medicine.  
Changing Lives.®



## A new topic for the Our Questions Have Power program!

When it comes to MS symptoms and how to manage them, what questions are most important to you? What symptom-related topics do you wish researchers were studying? **Your questions are valuable** and we invite you to share them through the **Our Questions Have Power** program on the [iConquerMS](#) website.

[The Our Questions Have Power program](#) was launched in March 2021 with an initial focus on COVID-19. Questions submitted by iConquerMS members have helped shape the [COVER-MS vaccination study](#) and are being shared with the research community to guide other efforts.

We're now extending Our Questions Have Power to include a second topic: **MS symptoms and their management and treatment**. As before, you're invited to share questions on this topic that you think should be studied and to vote on questions submitted by other iConquerMS members. We'll share these questions with people affected by MS, researchers, healthcare professionals, advocates, and funders – and, together, we'll work to launch research studies to answer those questions.

It's easy to  
share your  
ideas and  
input in Our  
Questions  
Have Power!

Log in to iConquerMS to start (create an account first if you don't already have one).

Click **PROPOSE** an **MS Research Question** to submit a question you'd like to see studied.

Click **VOTE** and **COMMENT** on **MS Research Questions** to review, comment, and vote on questions submitted by other iConquerMS members.