

November 2022 Newsletter



When MS Begins Later in Life

MS doesn't discriminate when it comes to age. According to the [National MS Society](#), most people are diagnosed between the ages of 20 and 50 years, however it can present outside of this age bracket. In rare cases, MS is diagnosed in childhood or later in life. When the onset of disease occurs at 50 years or older, it is called **late-onset MS** (LOMS).

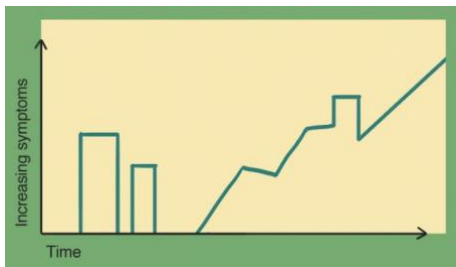


[Diagnosing MS](#) can be difficult at any age but there are additional challenges as one gets older. There is [evidence](#) that LOMS is frequently misdiagnosed because its symptoms are often mistaken for signs of normal aging. A number of studies have looked at the symptoms and prevalence of LOMS. A [recent review](#) concluded approximately 5% of people with MS are diagnosed at ages above 50 years old, more often in woman than men. Authors state



that more people with MS in this age bracket present with progressive forms of the disease and their first symptom is usually [motor dysfunction](#). A [2014 study](#) found LOMS occurs in 3.4% of people living with the disease, again, more often in women than men. Results show relapsing remitting and progressive MS are nearly equally common when the

disease starts later in life. A [2020 study](#) compared early-onset MS (EOMS – onset before 18 years of age), adult-onset MS (AOMS – onset between 18 and 50 years of age) and LOMS. Data showed the key features of LOMS are motor dysfunction, [sensory disturbances](#), and visual impairments. 25% of participants with LOMS transitioned from relapsing remitting MS to secondary progressive MS an average of 14 years after disease onset. Compared to individuals with EOMS and AOMS, those with LOMS had no relapses in the first two years and higher EDSS scores at disease onset.



There is evidence that MS progresses faster when it develops later in life. A [2016 study](#) determined that people with LOMS reached an [EDSS score](#) of 6.0 significantly faster (6.5 years after disease onset, compared to 12.8 years for people with AOMS).

Results showed the risk factors for a more aggressive disease course were being male and having spinal cord lesions at MS onset. On the other hand, LOMS isn't necessarily associated with a worse outcome. According to a [2006 study](#), even though participants with LOMS reached an EDSS score of 6.0 faster, they were much older when they reached that milestone (71 years old) compared to those with AOMS (58 years old). Advanced age may have been a confounding factor (discussed below). Investigators state that disease course (relapsing versus progressive) has a far greater implication for an individual's prognosis than a later age of onset.

LOMS and AOMS likely share the same [causes](#), which are not yet fully understood. Scientists have determined that a variety of factors, or combination of factors, make an MS diagnosis more likely. For example, although MS is not a hereditary condition, people may inherit a susceptibility to developing it. Genetic risk factors, coupled with environmental factors like low vitamin D levels, smoking and obesity, increase the risk of developing the disease. Interestingly, [researchers](#) in Sweden compared the familial (hereditary) risk of EOMS and LOMS. They found no significant difference between the two. More research is needed to understand the exact causes of MS, how they work together and why some people develop the disease later than others.





It's important to note that normal aging can affect many aspects of living with MS. There is [evidence](#) that age affects a person's ability to recover from MS relapses (which is a critical factor in disease progression). This could be due to a complex process called [immunosenescence](#), which is discussed in our [July 2020 newsletter](#). In short, the immune system functions less effectively as a person gets older. Its repair capacity decreases and nerve degeneration often occurs, which can hasten the progression of MS over time. Another typical aspect of aging is the development of a chronic, low level of systemic inflammation (often referred to as [inflammaging](#)), which has a similar effect. People with MS often have [other medical conditions](#) and their incidence increases with age. Managing multiple health conditions poses a challenge to people with MS and their health care providers. Teasing out symptoms and determining which are due to MS and which are due to another health condition is often difficult. MS treatments may also interact with medications required for other illnesses. This has the potential to delay MS diagnosis, affect treatment and cause more rapid disease progression.



Treatment of LOMS includes the same approaches as AOMS, namely [disease modifying therapies](#) (DMTs), [managing MS relapses](#) and [rehabilitation](#). Historically, MS clinical trials have had age restrictions that have limited the participation of older people with MS (resulting in missing important data). As a result, information about the efficacy and safety of MS DMTs in this population is limited. Research into the use of [interferon \$\beta\$ -1b medications](#) (Betaseron, Extavia) has returned mixed results. A [2015 study](#) showed these drugs do not significantly slow disease progression in people with MS over the age of 50. [Subsequent research](#) suggests they are an effective and well-tolerated treatment option for individuals with MS between the ages of 40 and 72. [Research](#) into the efficacy and safety of [ocrelizumab](#) (Ocrevus) in persons with progressive MS inclusive of people up to age 65 years is ongoing.

A prompt and accurate MS diagnosis is critically important at any age. Early treatment helps to prevent disease activity and the accumulation of disability. The distinctive features of LOMS should be taken into consideration when choosing a treatment plan, including existing comorbidities and any age-related symptoms. The available data regarding the effectiveness of DMTs in older people with MS remains sparse and further studies in this age

group are necessary. The core of ACP's mission is to facilitate research efforts into topics such as these, which have the potential to improve the health and quality of life for people living with MS throughout their lifetime.



[READ MORE >>](#)

**Want to learn more about aging with MS?
Revisit past newsletter articles on this important subject!**



Aging Gracefully With MS



The Senior Moments of MS



Does MS Weaken With Age?



Is Menopause a Turning Point
for Women with MS?



Too Old for MS Treatment?

Building an Unstoppable Team

A board of directors is a body of elected or appointed members who, together with the CEO, oversee the activities of an organization. An effective decision-making board can strengthen a nonprofit organization in many different ways. It can oversee strategy and tactics, perform some of the tasks of the organization, support the organization's work in its community, bring necessary resources for better performance, advise the organization on financial, legal or other matters and help with fund raising. At ACP, we are blessed with a board that matches these ideals, and then some. Our Board consists of a diverse group of 8 generous people with different educational backgrounds and areas of expertise, each of whom cares deeply about accelerating MS research. Together, they form the backbone of ACP.



ACP's initiatives are strategic tools for accelerating MS research. The ACP Repository is a collection of thousands of biosamples and associated data that also has millions of returned



data points deposited for the benefit of all researchers. It is a rich resource that is readily available to help scientists determine the biological underpinnings of the disease. iConquerMS engages people with MS and their loved ones to participate in research by sharing their health information, completing questionnaires on a

variety of subjects and connecting with researchers by an online portal. This powerful initiative adds a vibrancy to MS research by infusing it with the perspectives of those affected by the disease and focusing studies on topics that matter most to them.

We, at ACP, believe that research is the only way to greatly improve the outlook for people with MS and one day find a cure. Data collection and sharing are key in the research process. ACP's programs catalyze MS research by inexpensively providing the "raw materials" scientists need to explore their ideas quickly. We promote open access principles so that information flows freely to those who can optimize its impact. An effort of this magnitude requires a variety of skills, including strategic planning, marketing proficiency, financial wisdom and legal expertise. ACP's leadership is up to the task.



Linda Kanner has served on the ACP Board for the past 15 years and held the position of Board Chair from 2019 - 2022. She is a retired entrepreneur and a communications/marketing professional with expertise in new product development and sales management. She has broad experience building businesses and managing both start-up businesses as well as large corporations. She shares, “I have MS and my uncle had debilitating MS. I was introduced to ACP when I was diagnosed and was intrigued by the vision to cure MS through collaboration between patients and doctors... I am an entrepreneur and am excited to bring “newness” to this fight. The vision of iConquerMS speaks to me... I have great respect for the research community and feel that supporting the best MS academic researchers is likely to bring results. I have children and grandchildren who carry my MS genes and I want this disease to be cured!”



Michael Middlebrook joined the ACP Board in 2020. He is an investment analyst with a background in healthcare management consulting and investing. In his words, “The ACP Board is a talented and diverse group of individuals from a range of backgrounds that are all committed to accelerating a cure for MS. It's an energized group that's focused on increasing ACP's awareness and maximizing its impact on the MS research community... I often think about the financials of ACP, how we can effectively support large research organizations in a way that supports our (and their) internal financial requirements so we can continue to grow ACP and our partners' impact and reach... ACP has the opportunity to create research assets that can be shared among for-profit and non-profit pharmaceutical, medical device and research institutions - it's uniquely positioned to support and spur research in a way that most other healthcare research institutions aren't able to.”



Patrick Curley joined the ACP Board 6 years ago and serves as the current Board Chair. He has a vast amount of legal expertise as a Certified Elder Law Attorney, whose law practice focuses on helping seniors and those with special needs, including those with chronic illnesses like MS. As a small business owner, he is well versed at leveraging and maximizing what can be accomplished as an organization with limited resources. According to Patrick, “My legal background helps me with analyzing complex information and developing strategies. When I learned about ACP, I immediately knew that I wanted to serve its mission. ACP is doing something no one else is. Its biorepository is accelerating research towards better treatments and a cure, while iConquerMS offers a vigorous community, both nationally and internationally, for people affected by MS to work together with researchers and pharmaceutical companies to truly target research to the needs of our community. I am very excited by the combined potential of these initiatives to push scientific achievement toward improved treatments and, ultimately, a cure for those living with MS... I have been very active in scouting with my son and am an Eagle Scout myself. One of the core elements of scouting is doing good for others and doing your best. I try to bring that same mindset to ACP.”

ACP’s Leadership is also rich with scientific expertise.

Aakruti Sangeev is one of the newest members of the ACP Board. She brings to the table years of experience working in the pharmaceutical industry as a scientist and project manager in Neuroscience and Oncology. She is currently the Director of Program Management at a Biotech company. She shares, “Neuroscience is near and dear to my heart and I feel honored that I get to utilize my skills and knowledge to better serve the MS community.”



Peter Riskind has served on the Board since 2016. He is a retired neurologist that cared for people with MS for more than 30 years. He founded and directed the MS Center at



UMass Memorial Medical Center and also conducted MS research as a Professor of Neurology at UMass Medical School. He was an original site Principal Investigator for the ACP Repository. When asked why he serves on the Board, Peter states, “I am excited by the unique approach that ACP (and now also iConquerMS) has taken to accelerate MS research and to include viewpoints that were not being recognized adequately before. I feel strongly that ACP can

make major contributions to MS research and to the MS-community and I am honored to play a small role in this effort.”

New to the Board this year, **Deepak Grover** is a data scientist with previous experience working in the MS realm in the pharmaceutical industry. His knowledge and skills are instrumental in leveraging the wealth of information in the Repository and iConquerMS databases for the most impact, among other things. In his words, “I have been a manager



and group head in my professional career where I have had opportunity to initiate, manage and run programs to fulfill the mission of the organization. There is no question that collaboration across and between industry and academia, and enhanced availability of scientific data and biological samples will accelerate the path for getting an effective cure. It is truly heartwarming to see ACP is actively engaged in that direction.”

Fewer than 10 percent of people enrolled in clinical trials today are minorities. Diversity in MS research is vital to ensure that its findings apply to and benefit everyone living with the disease. In March, the ACP Board welcomed an individual that is well equipped to help drive these efforts forward. **Jerry Kinard** has worked in drug development for more than a decade. He is deeply involved in engaging with people affected by diseases and understands how to bring them into the research space. Jerry

states, “I am passionate about clinical research and how critical it is to get drugs to the market for patients who need them. I have worked in various therapeutic areas monitoring and managing clinical trials for several pharmaceutical companies. I believe I bring a unique skill set through my understanding of the clinical



research enterprise... I know as a leader that decisions are often made at the top that influence peoples’ lives that look like me (African American). I would like to bring my

lived experience and my research experience to the Board where I believe I can help bring value particularly as we seek to find treatments for diverse populations.”

In order for ACP to advance its mission, it is imperative to spread the word about the important work that we’re doing. Another recent addition to the ACP Board has the knowledge and skills to help us tell our story. **Kristy DosReis** is a professional communicator and collaborator for both public offices and non-profit organizations. She



specializes in taking complex information and making it understandable. In her words, “I understand the importance of clarity and passion when trying to reach and inspire audiences. As an individual diagnosed with MS in 2010, I face the challenges of this disease every day. I’d like to have an active role in the fight to accelerate MS research and, one day, a cure.”

ACP is strategically building a robust board that has the expertise that’s needed to move ACP and MS research toward a cure. Its membership includes a mix of old and new voices – individuals that have served for many years and new members with fresh perspectives. ACP’s leadership includes people with MS that not only understand the disease’s impact, but also the needs and priorities of the MS community, which is what our vision and mission is wholly centered on. All share a commitment and passion for research, a desire to lead and be a part of something bigger. With these individuals at the helm, ACP is well poised in its mission. We thank each of them for their service and look forward to what the future holds!



November 2022 Donor's Corner

Based on your feedback, we know you'd like to hear more about how your donations accelerate research for improved health and well-being for those affected by MS and a cure.

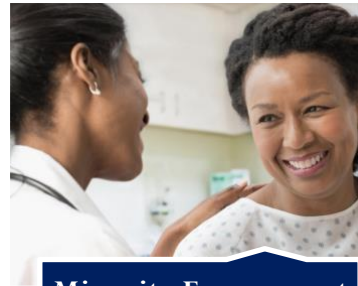
At the highest level, your generosity supports ACP's vital research resources:



ACP Repository



iConquerMS



Minority Engagement
in MS Research

Each month we'll shine a light on how you are accelerating research through these different avenues.

This month, we're highlighting how your generosity enables iConquerMS, the MS people-powered research network, and accelerates research that matters most to people affected by the disease. iConquerMS partners with those affected by MS to drive new ways of conceiving, designing, conducting, and disseminating MS research that centers on their needs and results in significant improvements in their health and quality of life.

In early November, ACP hosted the annual iConquerMS Summit and brought together more than 70 stakeholders, including people living with MS, caregivers, researchers, clinicians, funders, and others, for a 2-day virtual meeting to set the strategic direction for the initiative. The theme of the Summit was "Deepening our Impact" and attendees brainstormed approaches to ensuring MS research is infused with the insights, priorities, and perspectives of people affected by MS.

Curious? Stay tuned for a more in-depth article about the Summit in our January 2023 newsletter and read more about how iConquerMS is improving the health and quality of life for people affected by MS.

Thank You
FOR YOUR SUPPORT

November 2022 Research Spotlight

iConquerMS Spotlight

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Our Questions Have Power

How important is healthy living for people with MS? Don't miss the latest Chat with Chat webinar!

The Next Steps Committee of iConquerMS has launched a new webinar series called “Chat with Chat” and you’re invited! 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.



In November, Chat spoke with Nupur Nag, PhD from the University of Melbourne, Australia about “Assessing the impact of lifestyle behaviors on health outcomes in

people with MS.” Anyone interested in hearing this conversation can find the latest Chat with Chat webinar (Episode 9) [here](#).

In case you missed previous episodes of Chat with Chat:

In [Episode 1](#), Chat spoke about his own research into the aspects of MS drugs that people value the most.

In [Episode 2](#), Chat spoke with Nina Bozinov, MD MS, about "Measuring the Quality of Life of People With MS: Findings From the REAL MS Study."

In [Episode 3](#), Chat spoke with Farrah Mateen, MD PhD, about what we've learned from iConquerMS about COVID-19 and MS.

In [Episode 4](#), Chat spoke with Farren Briggs, PhD ScM, about “COVID-19 vaccine safety: A study from iConquerMS data.”

In [Episode 5](#), Special guest Hollie Schmidt spoke with Mitch Wallin, MD MPH, about “Telemedicine and MS: Perspectives from Patients and Health Care Providers.”

In [Episode 6](#), Chat spoke with Annabel Decamps from Icometrix, a company that develops software and services that help people view, store, and analyze medical images such as MRIs.

In [Episode 7](#), Chat covers the topic of how (and why!) to become a research accelerator. Hear from people living with MS, researchers, and members of the iConquerMS project team to learn how YOU can accelerate MS research!

In [Episode 8](#), Chat spoke with Sarah Minden, MD, PhD from Brigham and Women’s Hospital about "Use of complementary and alternative medicine (CAM) by members of iConquerMS".

A heartfelt thank you to Chat and his colleagues for making this educational resource possible. Stay tuned for future episodes!



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.



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](#) (5-10 minutes, we promise!) 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!



New REAL MS Surveys! Sharing Your Experience Matters

New REAL MS surveys have landed on your iConquerMS dashboard! Please [visit the site](#) today and fuel MS research by completing your open surveys.

In addition to accelerating MS research with your data (reason #1!), we'll also be able to tailor upcoming research opportunities for you (reason #2!). Knowing information about your demographics and MS history means that when the right opportunity comes along, we can reach out to YOU!

How to accelerate MS research (and make sure we can contact you with additional research opportunities):

1. Visit your [dashboard](#) (you'll be prompted to log in)
2. Click on the "View and Complete My Research Surveys" button
3. Complete your first open survey
4. Repeat steps 2 and 3 until you have no more open surveys!

If you run into any problems or have any questions, just send us an email at info@iConquerMS.org. Thank you for your participation! Your data – especially your REAL MS data – has power! Your health information is important even if you think things haven't changed much in the last few months.



**Visit My
Dashboard**



Help us understand the benefits of a home-based exercise program for African Americans with MS!

Research opportunity, University of Illinois – Chicago. This study involves the remote delivery of a 16-week exercise training program for rural-residing African-Americans with Multiple Sclerosis (MS).

Benefits of participating

- Learn about methods of improving your health and wellness
- Contribute to ongoing research on African Americans with MS

Eligibility

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

For more information:

Contact Edson Flores

(833) 727-1887 enrl@uic.edu



You are invited to participate in a research study comparing the effects of three diets!

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 attending the 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 to 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



**Your health data
has power!**

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.