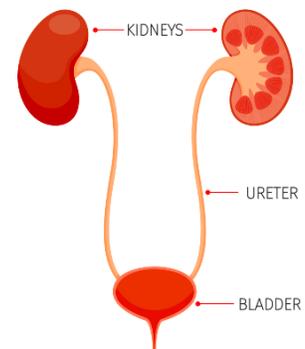


June 2021 Newsletter



When Nature's Call Goes Awry

A [recent study](#) found that almost 80 percent of people with MS experience bladder dysfunction. Results show these problems are associated with higher levels of fatigue and disability. Urine is made in the kidneys and travels down two tubes (called ureters) to the bladder. It collects slowly in the bladder, causing it to expand. When approximately eight ounces of fluid have accumulated, nerves in the bladder send signals to the spinal cord which, in turn, messages the brain that the bladder needs to be emptied. Bladder dysfunction in MS happens when nerve signals to the bladder and urinary sphincter are blocked or delayed because of MS lesions in the brain and/or spinal cord.



There are two muscles involved in emptying the bladder. The detrusor muscle surrounds the bladder and contracts to push urine out of the bladder. The flow of urine is controlled by the sphincter muscle at the opening of the bladder, which relaxes to open (allowing urine to leave the body) and contracts to close. There are two main types of bladder dysfunction relating to either the storage of urine or the emptying of urine. Some people experience a combination of the two. In people with MS, problems storing urine are caused by demyelination of the nerves controlling the detrusor muscle, causing it to

involuntarily contract, increasing the pressure in the bladder and decreasing the volume of urine the bladder can hold. This leads to symptoms like urgency (needing to go to the bathroom immediately) and frequency (needing to go to the toilet often) during the day and night (called nocturia). Bladder emptying difficulties occur when nerve impulses controlling the sphincter muscle are interrupted. This can result in hesitancy (difficulty passing urine) and retention (the inability to empty the bladder completely). Leakage of



urine can also occur when the sphincter remains partially open, resulting in involuntary leaks (incontinence). It's important to note that not all bladder issues are caused by nerve damage. Other causes include urinary tract infections, enlarged prostate in men, pregnancy and childbirth in women, abdominal surgery, and caffeine and alcohol consumption.

A number of lifestyle changes can help make bladder issues easier to manage. Some people find it useful to keep a diary of what they eat and drink, medications, when they go to the bathroom and any difficulties they may be experiencing. Keeping track of these things can help determine what, if any, difference diet or treatment changes make in this regard. These records can also be shared with one's healthcare providers. It's important to stay well hydrated. Dehydration leads to more concentrated urine, which can irritate the bladder and create a good environment for infection. On the other hand, drinking too much can make bladder symptoms worse, so getting the right balance is important. It is best to limit or avoid caffeine, alcohol, carbonated beverages, spicy food, and citrus fruit/juices as these can irritate the bladder. In order to avoid being up all night, it may help to limit drinks a couple of hours before bedtime. It's important to maintain a healthy weight and avoid constipation through regular exercise and a healthy, balanced diet. Being overweight can increase the pressure on the bladder and a full bowel can obstruct the flow of urine or affect the bladder's capacity. It may also help to stop smoking as nicotine is a bladder irritant.



While out and about, it may be helpful to plan frequent stops. A number of [mobile phone apps](#) are available to find the nearest bathroom. Using [protection](#), such as pads, can afford confidence, especially in situations where getting to the restroom could be difficult. It

may also be helpful to wear easily removable clothes, for example pants with elastic waistbands and bring a change of clothes, just in case.

Creating a routine can also help to avoid accidents. This involves eating and drinking at regular times and going to the bathroom after every meal or every few hours. [Bladder training](#) is a type of behavioral therapy to regain control over urination. It teaches an individual to hold urine for longer periods of time, allowing them to go longer between

Training



trips to the bathroom. It also helps to prevent emergencies and accidents. This involves establishing a regular routine for going to the bathroom, gradually increasing the time between visits. Individuals train themselves to resist the first urge to go and wait until their scheduled time. Eventually the time between restroom

visits increases and the urgency to get to one decreases. [Pelvic floor exercises](#) are a type of physical therapy that can be helpful for bladder control. The pelvic floor is a set of muscles that support the pelvic organs, like the bladder. When these muscles become slack it can weaken the bladder sphincter, allowing leakage of urine. A physical therapist can provide guidance on how to properly do this type of exercise.

A catheter is a thin, hollow tube that's used to drain urine from the bladder. [Intermittent self-catheterization](#) allows an individual to empty their bladder as needed. This involves inserting a catheter into the [urethra](#) to drain urine out of the bladder and immediately removing it. Cleanliness is a vital part of this technique in order to avoid introducing infections into the bladder. A [Foley catheter](#) is inserted into the bladder by a healthcare professional and is used to drain urine from the bladder

over a longer period of time. It has an inflatable balloon on the end that is inserted into the bladder which is filled with sterile water to keep it in place. A

[suprapubic catheter](#) (SPC) may be an option if long term catheterization is necessary. This involves surgically

inserting a catheter directly into the bladder through the abdomen. An SPC can typically be left in place for four to eight weeks before it needs to be changed or removed. It can be removed sooner if the individual is able to urinate on their own. Indwelling catheters like the Foley and SPC drain into an external bag, which has a valve at the bottom so it can be emptied.



Nerve stimulation is another technique that is used to help those with bladder dysfunction. [Research](#) shows that percutaneous tibial nerve stimulation is effective for symptoms of spastic or overactive bladder. During this procedure, a very small needle electrode is inserted in the ankle. The electrode transmits a signal to the sacral plexus (the network of nerves that controls the bladder and pelvic floor muscles). Typically, 12 treatment sessions are needed, lasting 30 minutes each. [InterStim®](#) is a small device that is surgically implanted under the skin in the buttock region and stimulates the sacral nerves. It recently received FDA approval for the treatment of overactive bladder, urinary retention and some types of bowel dysfunction.

If non-drug approaches don't provide sufficient relief, a variety of [medications](#) are available to address specific bladder problems. It's important for people with MS to work with their healthcare provider to select the best treatment approach. When oral medications aren't effective, an injection of [botulinum toxin](#) (BOTOX) into the bladder



wall is an option. This acts by stopping nerve messages to the bladder muscles and can freeze their contraction, improving urinary continence. The benefits generally last between 6–12 months after which the procedure can be repeated. It's important to note that the bladder may no longer be able to empty itself after treatment with Botox injections, making the use of a catheter necessary.

Surgery is typically only used as a last resort for bladder dysfunction that does not respond adequately to other treatments. [Culposuspension](#) (lifting the neck of the bladder and stitching it in place) or [sling surgery](#) (placing a sling around the neck of the bladder to support it) can be done to prevent leaks. A [detrusor myectomy](#) involves removing all or part of the detrusor muscle. This reduces the amount of and strength of bladder contractions. A [bladder augmentation](#), or cystoplasty, is a surgical procedure that makes the bladder larger.

Healthy bladder function is essential to overall health and quality of life. Untreated bladder issues can cause worsening of other MS symptoms, challenges with work, home and social activities and loss of independence, self-esteem and self-confidence. Available treatment options are effective for managing most symptoms of bladder dysfunction. It's

important for people with MS to discuss any they may be experiencing with their healthcare providers. Early medical evaluation is important to determine their cause and choose the best management and treatment strategies.



Fishing For a Cure

Volunteers make a huge difference in ACP’s ability to accelerate and advance MS research. We are grateful for hundreds of donated hours that support our work each year. Our volunteers help us with a wide variety of important tasks. Some are a tremendous help with administrative tasks and other projects. Others have hosted fundraising events to raise money that enables the work that we do. We are very grateful for these remarkable individuals who have freely given of their time and talents!



Michael Austin is from Alexandria, VA. His mother was diagnosed with MS just after he was born. When asked how MS has impacted his life, he states, “I’m very lucky to say that the impact has been minimal. I’ve seen my mom have flare ups in the past, her last one was six or seven years ago. It definitely worries you because you’re not used to seeing your parents, at least my mother, not able to do regular things or needing a lot of time to herself and time away from work or what she’s doing. You need to have a greater sense of responsibility in those moments and also patience.”

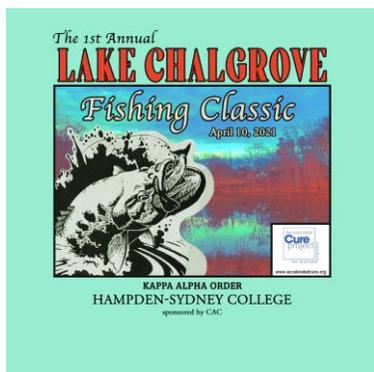


Michael is a rising junior at [Hampden-Sydney College](#), studying economics and business. When asked about his aspirations for the future, he shares, “I’d like to pursue a career in commercial development. I’m interested in manufacturing abroad, the import/export business, and how companies use resources on a global scale.” Michael is also active in Greek life at school and serves as the philanthropy chair and treasurer of his fraternity, [Kappa Alpha Order](#). In his free time, Michael is a big reader. In his words, “I like to stay informed. I love playing sports. Anything where I can be active and have fun. I love getting outside. I’m a big music person. Now that COVID restrictions are easing, I’ll definitely be going to a lot of concerts this summer.”

As an actor and officer of Kappa Alpha Order, Michael recently organized a fishing fundraiser on behalf of the fraternity to benefit ACP. On Saturday, April 10th, approximately 25 fellow students and fraternity brothers gathered on campus for the first annual Lake Chalgrove Fishing Tournament. It was a beautiful day and all in attendance enjoyed a day of fellowship, while seeing who



could catch the most fish! Hampden-Sydney College is located in a rural area and outdoor activities are popular with the student body. Lake Chalgrove is located near the main dining area and also backs up to some of the residence halls. Michael shares, “I’m in a community of people that are really big into the outdoors. The fishing tournament, for me, was understanding the target market, demographic of the student body, what people are interested in and the resources we have on campus. I’m not the biggest fisherman, I’ll admit. I’m just the man with the idea.”



Michael asked Baker Haviland, a fraternity brother with experience in graphic design, to make a t-shirt for the event. In his words, “We found an old article from the school newspaper with a graphic of a fish coming out of the water, did a different color scheme and used a tournament font to follow the theme.” Michael and his fellow students raised approximately \$1,100 to benefit ACP, primarily from t-shirt

sales. When asked why he chose ACP as beneficiary, “I started googling, searching what foundations and associations exist for MS causes. I contacted a few and really liked ACP’s transparency and focus on MS research. I think it’s important that any money that is raised goes towards the actual research and development of MS cures and treatments.”

Michael states that he hopes this is the start of a long and successful partnership with ACP. He would like to make this a reoccurring event and expand on his ideas in the future. In his words, “One of our intentions was to establish a relationship and a reputation with a philanthropic organization that we can work with over the next couple of years. Being able to fundraise on a consistent basis... I’ve marketed it is so people will know it will happen again. I’d like to get the staff out there and other people associated with the school. I want to make it something that the entire fraternity can get involved in.”

When asked what his biggest challenge was in organizing the fundraiser, Michael states, “I think just the timing and trying to make it line up with other events on campus. The space where we had it will be updated in the next year. They’re going to put in a stage for bands, so it’s going to look a lot better and, hopefully, attract more people for future events.” When asked what his favorite part of the day was, “Seeing people getting outside and doing what they want to do while also taking interest in what Accelerated Cure does and why I was raising money.”



We appreciate the contributions that Michael, and many others, have made in support of our work. Funds raised from events like these help us to continue our work to improve diagnosis, optimize treatment and find a cure for MS. If you have a favorite activity friends and family members enjoy doing or talents you would like to share, hosting a fundraiser is a great way to reach out to your community, raise funds for ACP and have fun while doing



it. For more information on hosting your own fundraiser, please contact Lindsey Santiago by phone (781) 487-0013, or by email lsantiago@acceleratedcure.org. We make it easy to support ACP in this way!

June 2021 iConquerMS Spotlight

Connect with iConquerMS Researchers

The Next Steps Committee of iConquerMS is launching a new webinar series called “Chat with Chat” and you’re invited! Hosted by our research collaborator Chat Ngorsuraches, these conversations will provide a glimpse at the researchers working with iConquerMS, what they study and why, and how their work will benefit people with MS.



The first webinar is scheduled for July 15, 2021 at 12 pm Eastern, and Chat will be talking about his own research into the aspects of MS drugs that people value the most. All sessions will be recorded and posted on our [website](#). If you’re interested in attending, please register here: <http://s.alchemer.com/s3/Chat-with-Chat-Signup>.

We look forward to the conversation!

June 2021 Research Spotlight

RESEARCH OPPORTUNITIES



UW Medicine
DEPARTMENT OF
REHABILITATION MEDICINE

University of Washington Community Health Study

The University of Washington’s (UW) Department of Rehabilitation Medicine is conducting a study to increase our knowledge about aging with a disability.

Participation in this study would include either 8 telemedicine visits with a wellness coach over 6 months or continuing with your normal care, as well as filling out 4 surveys over 12 months. You are eligible for financial compensation for surveys you fill out along the way.

Researchers at UW are seeking participants who:

- Are ages 45 – 64
- Have been diagnosed with a neurologic or muscular medical condition that creates difficulties or challenges in your daily living
- Experienced symptoms of this condition prior to age 40

Are you ready to learn more or get started? Contact the Research on Aging, Disability and Resilience (RADAR) Lab by calling 1-866-928-2114 or emailing communityhealthstudy@uw.edu.



Diagnosed with Multiple Sclerosis within the past 3 years?

What is it?

The Coping & Adjusting to Living with Multiple Sclerosis (CALMS) study is looking for adult participants diagnosed with MS within the past 3 years.

What is involved?

This study involves 1x week telephone or video Cognitive Behavioral Therapy (CBT) sessions with a counselor for 7 weeks, completing questionnaires and game sessions (receive up to \$175 for completing questionnaires and games).

Eligibility:

- 18 years of age
- Diagnosed with Multiple Sclerosis within the past 3 years

- Experiencing feelings of unease/stress regarding the recent MS diagnosis
- Read, write, and understand English

Interested in participating?

Contact the study team at 1-866-928-2114 or CALMS@uw.edu.

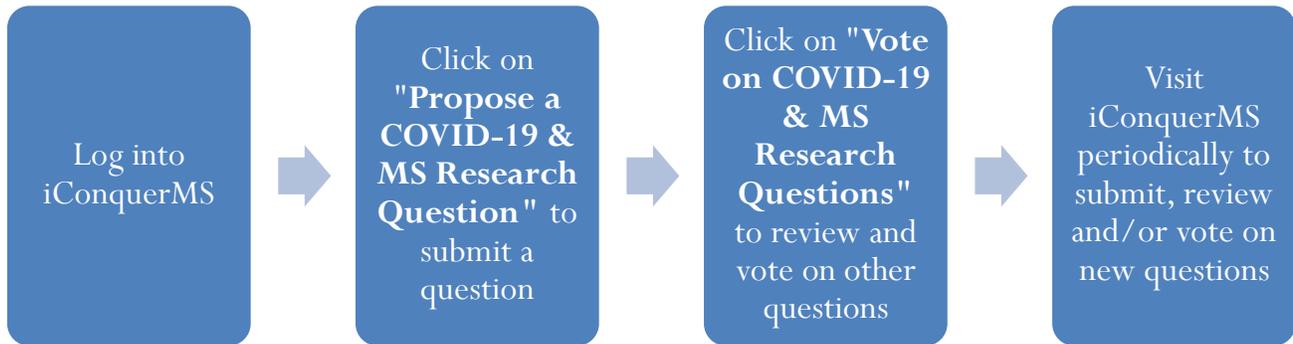


Announcing a New Program for iConquerMS Members!

iConquerMS is leading the movement to include the patient perspective in every step of MS research. Now, network members can play a larger role than ever before in initiating and collaborating with researchers on studies that will expand knowledge in areas that matter most to people affected by MS.

iConquerMS members have always been able to submit research questions to the initiative. It's now possible to comment and vote on questions submitted by the community through the newly launched [Our Questions Have Power](#) program. Questions that are high priority for the iConquerMS community will be shared with researchers, who will work in collaboration with the iConquerMS community to develop them into research studies.

Participation is easy!



If you are not already a member, please consider [joining](#) iConquerMS, the only people-powered research network for MS. Add your voice to those working together to improve MS care and bring us closer to a cure!



Share your experiences with COVID-19 vaccines

[iConquerMS](#) is now collecting information from people affected by MS related to their experiences with COVID-19 vaccines. The data collected will be securely shared with researchers studying the effects of COVID-19 vaccination on people affected by MS. If you are an iConquerMS member that has received a COVID-19 vaccine, please [login](#) today and share your experience by clicking on “Participate in the COVID-19 Vaccination Study.” Not yet a member? Please [join](#) iConquerMS now and start adding your