

March 2023 Newsletter



Small Miracles in Life Exist

In the summer of 2022, Sara, ACP's CEO, visited long-time ACP supporters, [Kemp Jaycox and Cindy Fink](#), on Cape Cod. When she arrived, she was struck by the accessibility of the beach house they were staying in. After remarking about this, Kemp and Cindy told her the beautiful property they were staying in is available through SMILE Mass.

[Small Miracles in Life Exist \(SMILE Mass\)](#) is a 501(c)(3) non-profit organization dedicated to helping children and adults with disabilities, and their families, enjoy happy, healthy memories through vacation and recreation experiences.



SMILE Mass was created in 2009 by two women with a personal interest in improving the lives of those with special needs. Lotte Diomedede's son, Nicholas, was born premature with a buildup of fluid on his brain ([hydrocephalus](#)). This condition typically causes increased pressure within the skull, resulting in brain damage. Susan Brown's daughter, Kristen, had



brain surgery when she was 3 years old for seizures that could not be controlled with medication. As a result, she is developmentally delayed with some mobility issues. SMILE Mass was born out of a simple goal – to install a handicap accessible swing at a playground in Sudbury, MA so that

Nicholas would be able to enjoy the park alongside his younger sister and friends. The people in town rallied behind this goal and it evolved into constructing an entire playground that children of all abilities could enjoy. In Lotte's words, "I'm a firm believer that the first place that you learn, make friends, and become part of the community is often the playground, especially when you live in suburbia. For thousands of families living with kids like my son, that's just not a possibility because playgrounds are not accessible. Nobody is playing with them and they can't get on the equipment. This is just wrong." The SMILE playground is now a landmark in Sudbury and a model for towns across the Commonwealth and beyond. To date, SMILE Mass has helped to build seven fully accessible playgrounds across the area.

Regardless of a person's age or ability, there is something special about spending a relaxing day at the beach. Unfortunately, most are not handicapped accessible.

In 2010, Lotte and Susan turned their focus to allowing people with special needs the same pleasure by donating a [floating beach wheelchair](#) to every public beach on Cape Cod that requested one. To date, SMILE Mass has donated



180 floating beach wheelchairs to public beaches throughout New England. The SMILE Mass [equipment loaner program](#) was started as an extension of the beach wheelchair program. Their inventory includes: floating beach wheelchairs, adapted bicycles, snow sleds, jog strollers, portable ramps, a bath chair and a Hoyer lift. Anyone with a disability can [borrow](#) this specialized equipment to use for a day or a week, at home or on vacation.

Lotte believes that everyone should be able to go on vacation, relax and have fun with friends and family. Unfortunately, finding fully accessible facilities with the right amenities can be very difficult for those with special needs. If found, they often come with extra fees that make it difficult for many families to afford. In 2018, SMILE Mass acquired the [town](#)



[house](#) where Kemp and Cindy vacationed in Truro, MA. Cindy grew up visiting Cape Cod with her parents and fell in love with vacationing there. Due to the progression of Kemp's MS, travel has become incredibly difficult which has robbed their family of something they always enjoyed doing. Cindy took their daughter, Kate, to the Cape twice without Kemp, but felt guilty being there

Kemp Jaycox, Cindy Fink and their daughter, Kate, vacationing on Cape Cod



without him. One night she Googled “accessible beach houses on Cape Cod” and discovered SMILE Mass. Kemp shares, “Thanks to this organization, I have been able to enjoy two vacations which otherwise would have been impossible. I can sit in my wheelchair on platforms and look out at the beauty of Cape Cod Bay. And with the help of my caregiver and my family, I was able to transfer to the beach wheelchair and stick my feet in the sand for the first time in eight years. My family and I are incredibly grateful to Lotte and Susan for everything they do to assist families like ours!” The SMILE Mass beach house is a fully

handicapped accessible space right on the beach that is designed to accommodate people with a wide range of disabilities. This beautiful vacation home is available for [rent](#) to families with a disabled member, with financial assistance provided to those who qualify.

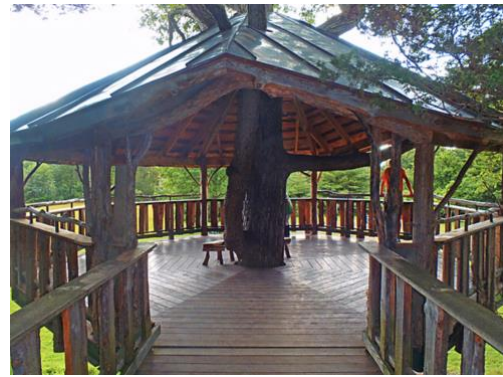
SMILE Mass also offers a wide range of classes designed to stimulate their clients both mentally and physically. The [Club SMILE Mass](#) programs are currently run out of [Lifetime Athletic Metro West-Boston](#). They offer in-person exercise options such as one-on-one training, small group workout classes, biking and swim lessons. Other activities include music therapy, story time, bingo and book club. Participants have the option of participating in many of these activities remotely via Zoom. All classes are run by certified staff. To ensure the appropriate support and safety of each participant, an intake evaluation is done and any necessary adapted equipment is loaned to the client while they are part of the program. According to Lotte, “Club SMILE Mass is a movement club. Anyone with a disability can participate. Currently our youngest client is 4 and our oldest is 59... The reason we call it a club is because I want to do things that are ‘normal’ for our kids. Just because they have disabilities, it doesn’t mean that everything has to have ‘therapy’ after the word. When they are with their friends on a typical Saturday night, I want them to be able to say, ‘Tomorrow I am going to club SMILE Mass and having swim lessons.’ I just want it to be normal. We call it swim lessons, but we work on functional movement. It’s easier to move in the water than it is on the ground. We work on water safety and skills building.”



Anyone interested in SMILE Mass programs can find more information on their [website](#), or by [contacting](#) Lotte directly. The organization currently services approximately 30,000 families, mostly in New England, but some of their clients are much farther away.

According to Lotte, “Our beach wheelchair program is used more broadly than any of the other programs. We have clients in Norway and Italy and a couple of families from AZ and CA. If a long-distance family needs a beach wheelchair, we ship one to them. When they are done with it, they ship it back. We don’t charge for the product itself. They only have to pay for the shipping. If a family needs a wheelchair delivered, we charge \$25 an hour. If they are picking it up, it costs nothing to borrow one.”

SMILE Mass programs are currently scattered across multiple venues. The organization is in the process of acquiring property in the metro-west area of Massachusetts on which to establish their [Community within a Community](#). This program will enable SMILE Mass to bring all of their services to one location. The property will include an adaptive and inclusive outdoor recreation area and there will be a pavilion where Club SMILE Mass classes can be held. Adapted equipment will be available for use on the property through the equipment loaner program. In Lotte’s words, “SMILE Mass started at my dining room table in Sudbury. It has now migrated to my basement and we are outgrowing every inch and corner of the house. We are slowly but surely setting ourselves up for the next big thing, which would be our Community in a Community. Families raising children and adults with disabilities will have the opportunity to join a club in their community, just like anyone else, hopefully fostering friendships in the process.”



When asked what her biggest challenge is, Lotte states, “SMILE Mass is growing faster than we can think, so it’s really hard finding quality staff and raising money fast enough.” Anyone interested in making a donation can do so by clicking the [donate button](#) on the SMILE Mass



website. The SMILE Mass VIP Coffee Club offers the opportunity to contribute the cost of a daily cup of coffee to SMILE Mass (drinking coffee isn’t required to join the club). Other ways to support SMILE Mass include [hosting an event](#) that benefits the organization or

joining the [SMILE Mass running team](#) at their annual road race. This year, SMILE Mass will have teams participating in the [Ragnar Relay NE](#) on May 19-20th.

When asked what she enjoys most about SMILE Mass, Lotte shares, “These amazing humans drive me. They are crushing their goals and getting better. My favorite part is to challenge them. It’s all about building trust and knowing that they can succeed. It’s also providing hope and stability to their families. This creates a sense of normalcy in a world where it’s not normal to raise a kid with disabilities. We provide a platform where they feel worthy, included and where they can thrive and still grow. That is incredible.” When asked what her vision or hope is for the future, “Having all of our programs in one place in our Community within a Community will allow us to utilize our equipment and resources better and service even more people. I also want to continue to challenge cities and towns to look at what changes should be made to include every community member. It’s really my aspiration that the world becomes a little bit kinder and we are a little bit more flexible and help each other instead of always just worrying about the bottom line.”

In conclusion, Lotte shares, “I always say a smile can change somebody’s day. A smile can start a new conversation. A smile can start the relationship and it can end a fight. Sometimes it just takes a little bit of compassion and understanding for one another... We’re working toward giving families quality of life and a sense of hope and belonging, that’s why I want to build this facility. With the right tools, everything is possible. If you think it, you can believe it. If you believe it, you can make it. What I love the most about SMILE Mass is seeing how these families are thriving with the very little we can provide. I can only imagine when we have our own facility what we will be able to do. These kids don’t do what a normal 22- or 30-year-old does, but they are living, having fun, laughing and making friends. Isn’t that what life is all about?”



iConquerMS Kids

& Teens

March is Multiple Sclerosis Awareness month, a time to raise awareness, share information and support the scientists that are working to advance our understanding of the disease. [Pediatric MS](#) is relatively rare. According to the National MS Society, approximately 3 to 5 percent of individuals



with MS are diagnosed before the age of 16. Because of the comparatively smaller pool of pediatric study participants, and because research with children requires additional steps to ensure their care and protection, the vast majority of MS research focuses solely on adult populations. As a result, not much information is available on the long-term impact of pediatric MS, and the safety and effectiveness of its treatments in a younger population. At ACP, we're committed to changing that!



[iConquerMS](#) is a community of people with MS, their care partners, researchers, doctors, and others who have come together to understand MS and search for solutions. Members can confidentially share their

health information, questions, and ideas to inform and inspire [patient-centered outcomes research](#) (PCOR) and [clinical effectiveness research](#) (CER). iConquerMS recently expanded its community to include children, adolescents and their family members through the [iConquerMS Kids & Teens](#) program.

The insights and expertise of pediatric MS stakeholders were instrumental in the design and implementation of iConquerMS Kids & Teens. Three surveys were launched last year to obtain feedback about participating in research – one to individuals diagnosed with MS as a child or teen, one to their parents and guardians, and one to healthcare providers and researchers. Responses from youth with MS are summarized below:

...are interested in participating in research, particularly when it doesn't involve experimental drugs.

...are very interested in answering surveys and learning about research opportunities.

...are motivated by helping others, contributing to new MS breakthroughs, and learning about MS.

...have participated in research and learned about these opportunities through a variety of channels.

...are comfortable with their parents joining iConquerMS and having access to their accounts and data.

...are most easily reached via email and text.

To help keep iConquerMS Kids & Teens in sync with the pediatric MS community, these surveys will remain [open](#) indefinitely.

Pediatric MS stakeholders also play a key role in running the initiative. A [Steering Committee](#), consisting of teens with MS, a parent, and researchers, healthcare providers, and funders with interests in pediatric MS, oversees all aspects of the project. This group is co-chaired by ACP's CEO, Sara Loud, and [Emily Blosberg](#), a young adult diagnosed with MS at 15 years old. Emily is founder and executive director of [Mr. Oscar Monkey](#), an organization that helps kids with MS by providing age-appropriate resources, advocacy, and community.



iConquerMS Kids & Teens is open to any child or teenager with MS, their families and other relatives. Youth members are asked to complete an initial survey upon enrollment, to share a bit about themselves and their MS history. In the future, there will be additional opportunities for them to contribute information about their general health, family health history, nutrition, lifestyle and exposure to environmental factors. These data will be



confidentially shared to enable research to better understand how MS affects children and adolescents. Children and teens with MS are often not included in conversations about research so it may not reflect their priorities and preferences, nor address the outcomes of greatest importance to them.

iConquerMS Kids & Teens empowers youth with MS to propose research questions and priorities to the research community, paving the way for relevant and impactful pediatric MS research.

Youth diagnosed with MS and their loved ones face a great deal of uncertainty living with a chronic and unpredictable disease. iConquerMS Kids & Teens offers resources to learn more about the disease, including answers to [common questions about MS](#). [MS 101](#) is an educational series that provides information about navigating life with MS as a young person. The topics covered are developed in collaboration with a diverse community of kids, teens, and young adults who are living with MS and who provide their insights as to how to develop and implement meaningful and useful content for all. We'll continue to add new content and resources based on the needs of the Kids & Teens community.



iConquerMS is the only MS people-powered research network that is driving, shaping, and accelerating research into topics that matter most to the people affected by the disease. Increasing pediatric participation in iConquerMS will allow investigators to conduct studies to address the unique needs, interests, and priorities of children and teens living with MS. This previously overlooked age group knows their disease better than anyone. Data about their daily experiences, symptoms and clinical treatment will help to create a key resource for research. Insight from youth with MS and their families regarding research topics they deem important will help to bridge the gap between the MS and research communities. Every piece of data expands the pool of information that researchers can draw from and every voice matters. We are stronger when we all work together. Are you a child or teenager with MS, or one of their loved ones? Please consider [joining](#) iConquerMS today! Do you still have questions, or are you a researcher interested in pediatric MS research? Please [contact us](#) to learn more.



March 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**

iConquerMS is a [people-powered research network](#) designed with and for MS stakeholders. The initiative empowers all people living with MS to drive, shape and participate in research studies and related activities aimed at better understanding MS and finding solutions that mean the most to them. Thanks to your generosity, we're expanding iConquerMS to better meet the needs of the MS community.



iConquer MS Kids & Teens

iConquerMS has been expanded to include children and adolescents with MS, and their families. This program is guided by pediatric MS stakeholders to ensure their insights and expertise are at its core. We are partnering with pediatric MS researchers and healthcare providers to support their work.



Calling All MS Caregivers

We heard from our community about the important role of MS caregivers, both at home and in the research environment. iConquerMS continues to expand its outreach and research collaborations to include MS caregivers, in hopes of easing their burdens and improving MS research in the process.



Research Results at Your Fingertips

There is a lack of information available for people affected by MS regarding research results and how they can be used to make decisions about living with MS. At ACP, we're committed to changing that! We recently received a capacity building award to enable iConquerMS to disseminate the results of PCORI-funded MS projects! Stay tuned!

[Join](#) our team and consider making a [donation](#) today! Together, we are working to improve the health and quality of life for everyone affected by MS.



March 2023 Research Spotlight

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.

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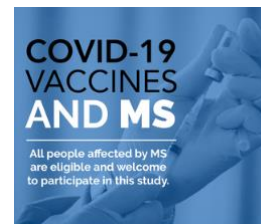
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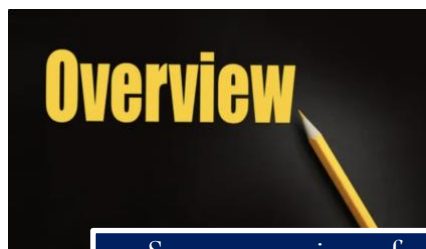
COVER-MS Update

How effective are COVID-19 vaccines in people with MS?

[iConquerMS](#) is gathering important information about COVID-19 vaccines and how they work in people affected by MS. The [COVER-MS study](#) currently has over 1,600 participants. This [real-time data display](#) summarizes the information they have provided to date. Overall, [results](#) show the frequency of vaccination reactions in people with MS is similar to that reported in the COVID-19 vaccine clinical trials.



Want to learn more about what we've learned from COVER-MS so far?



See an overview of
COVER-MS results

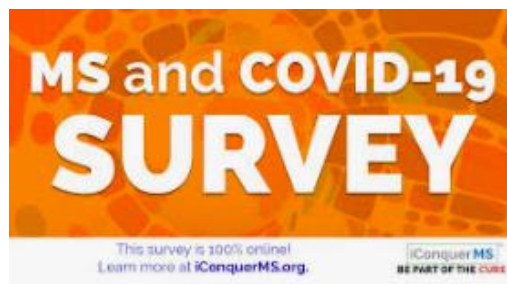


Watch Chat with Chat,
Episode 4

**BUT WAIT
THERE'S
MORE!!**

Through a partnership with Quest Diagnostics and the National MS Society, we've recently launched a [COVER-MS sub-study](#) looking at the effectiveness of COVID-19 vaccines at preventing the virus in people with MS. 300 COVER-MS participants will donate blood every 6 months for the next 2 years. These samples will be analyzed to determine how MS drugs and other factors affect the immune response (antibody levels) to COVID-19. We are currently inviting participants to return for a second blood draw and have been able to provide them with antibody results from round one. Analysis of these data is underway, stay tuned for the results!

COVER-MS is open to anyone who has received a COVID-19 vaccine or plans to receive one. To join the study, [log in](#) to your iConquerMS account. Not already a member of iConquerMS? Please consider [joining](#) today! Thanks for your help in conquering COVID-19!



RESEARCH OPPORTUNITIES



Behavior Change Program for Promoting Physical Activity in Persons Newly Diagnosed with MS

Researchers at the University of Alabama at Birmingham are conducting a behavior change intervention to promote lifestyle physical activity among persons diagnosed with MS within the last 2 years. The researchers aim to examine the effects of the program in helping persons newly diagnosed with MS increase physical activity levels. This study's findings can guide the development of more comprehensive and effective physical activity programs for individuals newly diagnosed with MS.

Participants will take part in a 12-week lifestyle physical activity behavior change program remotely delivered via email and Zoom one-on-one chat sessions. Participants will also complete two assessments of physical activity and MS outcomes before and after the program. All information provided will remain confidential. The researchers are seeking participants who:

- Are 18 years of age or older.
- Diagnosis of MS within the past two years
- Able to walk without assistance
- No relapse within the last 30 days
- Currently physically inactive
- Internet and email access
- Able to read newsletter with a font size of 14 points
- Currently on an MS treatment (DMTs)

Participants will receive compensation of \$50 for their time and effort.

If you are interested in participating in this research or would like to learn more about the project, please get in touch with **Lexi Huynh** at enrl@uabmc.edu.



RESEARCH OPPORTUNITY

University of Illinois - Chicago

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



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

For more information,
contact Edson Flores

(833) 727-1887
enrl@uic.edu

Keyword: TEAAMS

<https://projectteams.ahs.uic.edu/>



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

→ wahls.lab.uiowa.edu/join-study



Changing Medicine.
Changing Lives.®



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!



**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.