

Hilton Center's reach



Programs aim to empower people with multiple sclerosis.

by Shara Rutberg

Frank Miyamura, 73, tracks mountain lion P-61 as it crosses the 405 Freeway in Southern California. Along with nearly a dozen other members of his cognitive therapy group at the Marilyn Hilton MS Achievement Center at the University of California, Los Angeles, he's following the big cat's progress via motion-triggered camera photos and stories on an iPad.

Following a discussion, the group will answer questions about the lion's journey. Then, they'll be asked to recall details in a few weeks and again in a few months. The exercise "improves our memories without feeling like we're really 'working' at it," says Miyamura, who has primary-progressive multiple sclerosis.



Frank Miyamura takes part in the exercise programs provided to Hilton Center members. Photo courtesy of the Hilton Center

Cognitive therapy is just one type of session Miyamura enjoys during the day he spends at the center each week. As part of the center's flagship REACH to Achieve program, his group cycles through a schedule of cognitive, recreation, exercise, yoga, art and music therapy, as well as MS-focused educational sessions. "This is the highlight of every week," Miyamura says of his day at the center.

The Marilyn Hilton MS Achievement Center was founded in 2001 as a collaboration between the National Multiple Sclerosis Society and the UCLA Department of Neurology to empower people with MS through educational and experiential programs.

The program is made possible through major funding by the Conrad N. Hilton Foundation.

Conrad Hilton, who founded the Hilton hotel dynasty, created the foundation in 1944. The foundation made its first gift to the Society in 1957. Barron Hilton, who headed the hotel chain, made his own mark on the family foundation's focus on MS causes to honor his wife, Marilyn, who had MS.

Steve Hilton, Conrad's grandson and the son of Barron and Marilyn, is now chair of the foundation.



Steve Hilton Photo
courtesy of Steve Hilton

“I think by seeing how MS affects someone you love, it opened our hearts to not just my mom’s condition but anybody who has MS,” Steve Hilton says.

And while the foundation supports MS research, Hilton says the foundation also sees the importance of supporting the wellness and services aspects of MS care. “Lifestyle wellness, I think, is one of the most effective things that anybody can do to improve their situation. So that’s why [the achievement center] is a really great legacy for my mom,” he says.

Barron Hilton’s personal gifts to the Society total \$27 million. He died in 2019. Along with his gift, the Hilton Foundation has given more than \$70 million to impact MS wellness and research.

Elise Herlihy, executive director of the center and an MS nurse specialist, says the center offers a variety of educational and experiential programs designed for people living with MS, from those who are newly diagnosed to those who have been living with the disease for some time.

“We use a health and wellness model that complements their neurological care,” she adds. The center has a multidisciplinary team of professionals and volunteers that includes an MS nurse specialist, physical and occupational therapists, a recreation therapist and recreation instructor, a clinical exercise specialist, a dietician, a music therapist, speech and language pathologists, adaptive Iyengar yoga teachers, and mental health professionals. Sessions are all synergistic, with patients learning from the professional staff, as well as from one another.

The value of the center reaches far beyond its diverse sessions, says Medical Director Barbara Giesser, MD. “It’s a unique oasis for people with MS — a safe space, an empowering space, a nurturing space.”

The Living Well program is designed for people newly diagnosed with MS. “Most participants

are young adults, just starting with their lives when they get hit with the diagnosis,” Herlihy says. “It can be paralyzing. Most don’t know anyone else with MS. The program not only provides information and strategies they can use to take charge of their lives but also provides a community of support.”

The center’s flagship program, REACH to Achieve, is an ongoing, comprehensive health and wellness program designed for people who have been living with MS for a while and are facing multiple symptom-related challenges such as mobility, ability to cope, memory changes and deconditioning. Groups meet the same day each week from 10 a.m. to 3 p.m. for sessions including exercise, recreation, emotional wellness, cognition, and nutrition and health education. Sessions are fine-tuned to meet the needs of participants, from creating exercise routines on specialized equipment to adapting recreation activities.

Damian Washington, 38, learned about the Living Well Program about a year after his diagnosis of relapsing-remitting MS. He wishes he’d found it sooner. “The long way to learning how to live with MS is to try to figure it out on your own,” he says. “The short way is doing the program, where they already have everything codified.”

“It’s comforting, it’s reaffirming and it helps steel you for the future,” Washington says. The program fits into his personal approach to life: finding the joy and leaning into it.

Center members can choose from more symptom-specific, multi-week programs as well.



Joan Ishihara has been coming to the Hilton Center for 13 years. Photo courtesy of the Hilton Center

CogniFitness provides strategies for dealing with mild cognitive challenges that can accompany MS, including focus, memory, organization and problem-solving. Free From Falls

helps those who walk with or without a cane learn about risks for falls, how to reduce risks, and exercises to improve balance and mobility. Exercise and MS uses functional exercises to help those who are mobile improve overall wellness and help manage MS symptoms.

For those who can take advantage of the center's programming, the benefits stretch far beyond the UCLA campus. "The warmth of the group and the comprehensive programming is just far-reaching," says Joan Ishihara, 74, who has secondary-progressive MS and has been coming to the center for 13 years as part of the REACH program. "It keeps me going all week."

"It takes a lot of the fear, doubt and hopelessness out of our lives," Ishihara says. "We get to know each other and take care of each other beyond just our day at the center. It really fulfills me and makes me feel more confident about myself."

"It extends our ability to live independently," says Miyamura, who travels nearly two hours each way via Los Angeles' Access transit bus to reach the center. "It provides a safe harbor for asking questions and being asked questions, getting a different perspective on how MS affects each of us. The staff go out of their way to help us live our lives the best we can at whichever stage of MS. I'm very thankful for it."

Shara Rutberg is a writer in Evergreen, Colorado.

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