

Sylvia Lawry: Tireless crusader



National Multiple Sclerosis Society founder left no stone unturned in her crusade to find a cure.

by Robert Lerosé

If there was one philosophy that drove the late Sylvia Lawry, founder of the National Multiple Sclerosis Society, it would be the framed quote that hung in her office: “Never give up.”

Since its founding in 1946, the Society has raised over \$1 billion for research, setting the standards in diagnosis, symptom management and clinical trial strategies. Today, the Society, which recognizes 75 years of progress in 2021, has more than 500,000 volunteers, is a resource for the nearly 1 million people living with multiple sclerosis in the United States and leads the global charge to create a world free of MS.



The first medical board meeting of the National Multiple Sclerosis Society.

All of this was made possible because one determined woman with no medical background committed her life to establish an organization. She aimed to find a cure for MS in an era when women were considered second-class citizens, more fit for the kitchen than the conference room.

“She left no stone unturned to get people focused on MS and didn’t care who got the credit,” says Cyndi Zagieboylo, who began her career with the Society in 1985 and is now president and CEO. “I think that’s why MS has had more discoveries than any other neurological disease. It started from seeds Miss Lawry planted.”

Born Sylvia Friedman on June 28, 1915, in Brooklyn, New York, Lawry was the eldest of her siblings: Bernard, Alice and Lillian. Great responsibility came to her at a young age. When her mother was diagnosed with clinical depression, teenaged Lawry took over running the household and raising the children. She and Bernard, who excelled at both academics and sports, were particularly close. In 1937, at age 21, Bernard started having double vision and other telltale symptoms that led to an MS diagnosis, a condition that Lawry had never heard of.

At the time, she was attending Hunter College and preparing for a career in law, but she abandoned those plans to help Bernard fight the disease. When Bernard’s neurologists could

not offer much hope or a course of treatment, Lawry took matters into her own hands.

A movement is born

On May 1, 1945, she placed a small ad in the New York Times: "Multiple Sclerosis. Will anyone recovered from it, please communicate with patient." Instead of success stories, she received over 50 replies from families and individuals equally desperate for guidance and reliable information. Since little was known about MS, Lawry determined that research was the key to finding a cure. In March 1946, she founded the Advancement of Research on Multiple Sclerosis (later changed to the National Multiple Sclerosis Society in July 1947).



Sylvia Lawry and members of the Society staff at a conference in Harriman, New York, in 1959.

"I really had no idea what I was getting into. Our intent was to spend 100% of the money we raised on research. But I thought the path would be a much easier one than it turned out to be. I really believed this would be a short-term undertaking. Of course, I was wrong," Lawry said in "Courage," Richard Trubo's biography of her.

Setting up shop in an 8-by-10-foot office donated by the Academy of Medicine, Lawry reached out to prominent individuals for support, financial and otherwise. She regularly put in 12-to-15-hour days, resulting in the Society's first research grant of \$54,000. The project made an important discovery that accelerated knowledge dramatically. Believing that providing services to people with MS and raising funds were crucial on the community level, she extended the Society's reach to all 50 states. Under her leadership, the Society published manuals to educate the public on MS. She was building the Society during a time when there were few avenues open to women in the professional world.

Lawry learned firsthand that old prejudices die hard. In 1954, the new president of the Society asked her to relinquish her title of CEO because he believed "she didn't fit the male stereotype of someone capable of running a fast-growing organization," according to the

Trubo biography. Considering how much she had accomplished already, she was rightfully floored but complied nonetheless, putting the Society's goals first.

"None of us knew what the next day would bring. But there was always the hope the next day would provide the answer to multiple sclerosis," Lawry said.

Breaking boundaries

After testifying before the Senate in May 1949 with a stellar team that included the widow of baseball giant Lou Gehrig, Lawry pushed the government to start the National Institute for Neurological Diseases and Blindness (now the National Institute for Neurological Disorders and Stroke) in August 1950, securing millions of dollars for research.



Sylvia Lawry in her Society office in New York.

Whether she was talking to captains of industry, elite medical experts, celebrities or politicians, Lawry was relentless in asking for what she needed. She enlisted notables such as Shirley Temple Black, Frank Sinatra, Grace Kelly, President John F. Kennedy and Dr. Jonas Salk, among others, to her crusade. Recognizing that MS didn't stop at our nation's borders, in 1967, Lawry pushed for the creation of the International Federation of Multiple Sclerosis Societies which today includes more than 40 member Societies worldwide.

After living with MS for 37 years, Lawry's beloved brother Bernard died in 1973. Consumed by grief, Lawry renewed her efforts to bring hope to others. She stepped down as executive director in 1982 but remained secretary of the MS International Federation until 1997. Her two marriages ended in divorce and widowhood, but she raised two sons. Sylvia Lawry died on Feb. 24, 2001, at the age of 85.

Changing the world

Lawry may not have lived long enough to see a cure for MS, but her indomitable efforts paved the way for groundbreaking advances. The Society has recruited and trained more than 1,000 new MS researchers, doctors can diagnose MS much more quickly now, and more

therapies are available today than at any other time in history.



**Sylvia Lawry with her brother,
Bernard Friedman.**

As a direct, no-nonsense leader, Lawry also instilled confidence in the people who worked for her and brought out the best in them. “The thing that impressed me most about her was how ambitious she was,” says Weyman Johnson, former chairperson of the MS International Federation (MSIF). “At a conference, it was just the two of us sitting together. She pointed at me and just told me things I needed to do in Atlanta to make sure that we as an MS Society fully exploited all the resources there.”

Lawry was a private person, but sometimes colleagues saw behind what seemed to be a protective mask. Arney Rosenblat, who had an adjacent office in the communications department, remembers grabbing a bite with Lawry during long evening sessions.

“I always sensed a touch of sadness behind her eyes. Even while she talked glowingly of the many breakthroughs she helped shepherd, there was always this unspoken ‘but’ in the air that there is still no cure. When we sat down those nights to talk, it was there. It was very moving to me.”

Dolores Oria spent her entire career working at the Society, beginning in 1954 as a 17-year-old until her retirement in 2019. While it took her a long time to get up the nerve to talk with Lawry, Oria remembers getting some personal advice that stuck with her.

“As I was aging, she stopped me once in the ladies’ room and said, ‘You know, I don’t think you should ever let your hair go gray. You should always make sure you color it.’ She always wanted to look as young as she could. I guess I was starting to show some gray hair. All my years, I always dyed my hair,” Oria says.

“She was a slight woman, but she had this presence. Heads turned when she walked down the hall. She created a worldwide movement, and that is bigger than an organization,”

Zagieboylo says. “She engaged people and got them to carry the torch throughout the world. I think that’s her biggest accomplishment.”

Robert Lerosé is a writer in New York.