The Sonya Slifka Legacy:

A formal study of people with MS over time

BY CAROL MILANO

In a clinical trial, doctors and researchers gather data, then report the results—in their own language, not the participants'. The National MS Society's large-scale Sonya Slifka Longitudinal Multiple Sclerosis Study reverses that equation and gives us a unique perspective on the real-world impact of the disease.

"The Sonya Slifka Study collects people's own words about their experiences, and what's important to them," said Sarah Minden, MD, principal investigator of the study and assistant professor of psychiatry at Harvard Medical School. "People with MS talk freely about their illness, the quality of the care they receive, and the obstacles they have encountered in accessing care." Interviewers write it all down, verbatim.

The study was named in honor of the mother of the Society's past chair of the National Board, Richard Slifka. His generous gifts launched the study, and since 2000 it has followed a cross-section of America's population with MS. Telephone interviews, conducted every six months, yield firsthand information about the relationship between MS and the passage of time, and how, over time, this variable disease affects different people, their quality of life, social and family issues, and their use of health-care services and medications.

"MS is a disease people live with for 30 to 40 years. It's important to understand both its medical progression and what happens to people over the years," explained Nicholas G. LaRocca, PhD, the study's project officer and director of Health Care Delivery and Policy Research for the National MS Society. The Society has allocated more than $4 million for the Sonya Slifka Study.

Most long-term MS studies follow clinic patients, who may be further along in their MS progression, or who may have chosen care at a specialized MS clinic because they were encountering many problems. This skews the findings. The Sonya Slifka sample represents America's entire population with MS, at different disease levels, including those who are recently diagnosed. The average age of the study volunteers is 51.

The investigators, Abt Associates, Inc., of Cambridge, Massachusetts, were chosen through a rigorous competitive bidding process. Participation by people with MS is completely voluntary, anonymous, private, and confidential.

The study's design

Longitudinal, or long-term, studies are traditionally difficult to sustain. Participants drop out due to personal or physical problems, or because they simply lose interest. With almost 95% retention at each round of interviews, the Sonya Slifka Study has kept most of its 2,156 original participants.

Abt's specially trained telephone interviewers are particularly aware of MS's potential effects. The interview team has also remained loyal.

"They really enjoy this study," observed project director Debra Frankel, MS, OTR, of Abt Associates. "The same interviewer often calls a particular person for each interview, so it feels friendly."

Participants keep diaries to record details of their symptoms, medications and other purchases, doctor and hospital visits, home care, and days out of work or spent in bed. Interviews every six months reflect health-care usage patterns and any changes in MS. Because some people with MS develop memory or cognitive problems, background material (such as definitions of terms used in interview questions) can be sent beforehand, or read aloud by the interviewer. Phone appointments are arranged to suit each respondent's individual schedule—including evenings and weekends. When fatigue is a factor, interviewers offer to conduct the interview in separate segments, rather than in a single session. Interviewers are also taught to let a phone ring 10 times to allow a person who may move slowly ample time to reach it.

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The interviews consist of MS-specific questions, carefully worded so that every answer can be coded and analyzed. Abt staff checks with interviewers to learn about any confusing items. "Everyone needs to hear a question exactly the same way. Ambiguous language results in inappropriate answers," Frankel pointed out. For instance, during one round of interviews, the question was asked: "Why do you see this neurologist?" Replies ranged from "Someone referred me," to "His office is easy to get to," to "Because I have MS!" The wording was then modified to: "Why do you see this particular neurologist instead of some other one?"

How will the study findings help people with MS?

Data from the Sonya Slifka Study could have applications ranging from job retention to Medicare policies.

Employment. A high proportion of people with MS are employed when they are first diagnosed. The study investigates conditions that can jeopardize people's ability to work. "Once we know what those conditions are," Dr. LaRocca said, "we'll be better able to help by targeting the most important contributing factors. They may be discrimination, architectural barriers, cognitive changes, or something else."

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"We are exploring whether lack of workplace accommodations is the biggest barrier to continued employment," Frankel said. "The study is providing data on whether simple modifications can actually help people stay on a job." Some study participants told interviewers they were able to continue working following such changes as a parking spot nearer to their building, relocation to a first-floor office, a speaker phone, or a desk closer to the rest room.

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Medications. Are the MS disease-modifying drugs getting to everyone who needs them? "We don't yet know why some people are underserved by certain drugs," Dr. LaRocca said. "Are some doctors less knowledgeable about their use? Do reimbursement caps or partial coverage by third-party payers make them unavailable or unaffordable? The Sonya Slifka Study can identify what factors we should target to make these medications accessible."

Advocacy. Study findings will inform the Society's stand on public policies. "Many advocacy issues are long-term things you aim to change over time," Dr. LaRocca said. "Others are unexpected, like Medicare providing interim coverage for MS disease-modifying drugs. We have to be ready to provide current information quickly. Data from the Sonya Slifka Study have given us a much better idea of how many people with MS on Medicare lack prescription drug coverage."

The study is expected to spur Society activism by offering evidence-based "ammunition" for new or improved policies.

Some findings from the study

Sonya Slifka data have confirmed previous research in some areas, while breaking new ground in others. In exploring the health-care choices that people with MS make, the investigators learned that 70% see a neurologist, 18% see a primary-care physician, 7% see another type of provider, and 5% see no health-care provider for MS care. Patient satisfaction is apparently high: after 24 months, 80% of respondents used the same MS care provider.

When people with MS do not use recommended types of specialty care—such as seeing an occupational therapist or mental health counselor—what stops them? "Is the solution better patient education, or do we need to change the policies of third-party payers?" Dr. LaRocca asked. "We'll try to identify factors that might be creating barriers," he promised. The Society is committed to improving health-care delivery.

Comparing people above and below age 65, the study has found that people with MS over 65 were much less likely to have a regular source of MS care. They also tended to have progressive disease, more serious disability, and greater need

A special Promise: 2010 for the Sonya Slifka Study

In 1999, while longtime volunteer Richard Slifka was the chairman of the Society's National Board of Directors, he gave his fellow board members—and all the chapters that make up the Society—a powerful challenge. His gift of $1 million would start this ambitious study, which involves following a balanced sample of people living with MS over time.

How long is "over time"?

The Society's scientific advisors agreed that the duration and the level of investment in such a project would have to be reviewed regularly. It was vital to be sure that the study design was feasible in real life and that the emerging information was worth the expense required to obtain it.

To test the premise and bolster Richard Slifka's outstanding leadership gift, the Sonya Slifka Longitudinal MS Study became one of four targeted research initiatives for the Research Challenge of Champions. From 2000 to 2004, Society chapters raised more than $20 million to support the four initiatives.

Last year, the scientific advisors reviewed the Sonya Slifka Study again, asking hard questions about the quality and breadth of the data.

Targeted for Promise: 2010

The advisors deemed the Sonya Slifka Longitudinal MS Study important enough to continue as one of four selected targets for a new campaign, Promise: 2010. The January–March issue of **InsideMS** included an overview. The June–July issue will take a close look at the Pediatric MS Project, and later this year, the Nervous System Repair and Protection Project will be featured. The MS Lesion Project, previously detailed in **InsideMS**, and in an exciting 2004 Web cast archived on the National MS Society's Web site, is the other "continued" program.

To keep these targeted areas fully funded, the Society's chapters have pledged $29 million to be raised before 2010. Promise: 2010 is now reaching out to donors of every level. Call your chapter at **1-800-FIGHT-MS** and ask about it.

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for help with daily activities. The study showed that 85% of them received help but that only 40% received professional home-care services.

Confirming other studies of the use of disease-modifying agents, the study also found that about 50% of people with MS were taking a disease-modifying drug. Of those using one of the drugs, 78% experienced side effects. People with MS over 65 were far less likely to use them.

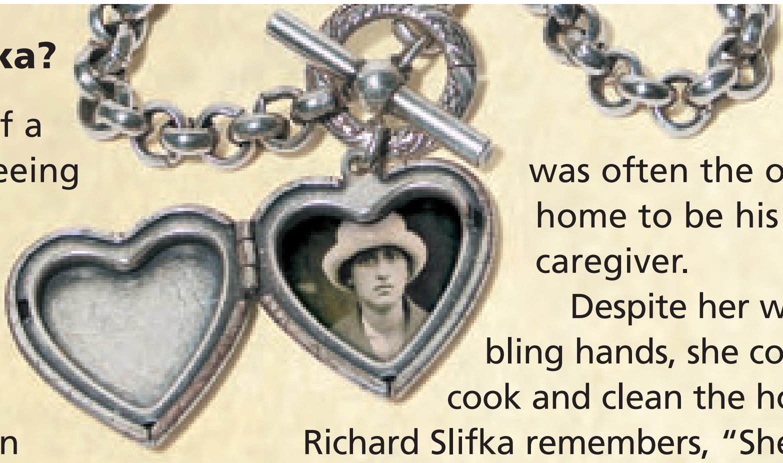
"We're now trying to understand why people either never took, or stopped taking, one of these medications," Frankel said. "Was it side effects? Insurance issues? Fear of needles?" Frankel hopes the Sonya Slifka Study will identify the barriers. "Are people using a disease-modifying drug more likely to work or live in a certain area? We haven't analyzed the data yet, but we're gathering it," she said.

"Disease-modifying drugs are all relatively new, and there's little information on them," said Dr. Minden. "No one's counted how many people with MS have used them, or explored the kinds of benefits and burdens people experience. It's exciting to learn things about an area no one has studied before."

"We appreciate the fact that our participants make a real commitment to do this study!" Frankel added. "People with MS are good research volunteers. They really want to help others." ■

Carol Milano is a free-lance writer living in New York City. This is her first story for InsideMS.

Who was Sonya Slifka?



Young Sonya was part of a great wave of people fleeing war and revolution in central Europe in the 1920s. She and some of her family settled in Boston, where teenage Sonya happily became an American. Shortly before the stock market crash of 1929, she married and began a family. Soon Sonya was working with her husband, Abe Slifka, building a business delivering home heating oil. Coal was king in those days, and the Depression made people loath to change to a cleaner but more expensive fuel. The young family had hard times, but by 1948 the difficult years seemed to be past. Both family and business were thriving. Then Sonya began experiencing disturbing symptoms: unexplained trembling, slurred speech, numbness, weakness.

In time, the diagnosis was made. MS. As it progressed, she lost more and more abilities—and Richard, her youngest son, now himself a teenager, was often the only one at home to be his mother's caregiver.

Despite her wildly trembling hands, she continued to cook and clean the house. And, Richard Slifka remembers, "She was always first in line if there was something new and exciting to see." But she hated MS for the limitations it imposed on her life—and so does Richard to this day.

The grown-up Richard Slifka, director and co-owner of Global Petroleum, in Waltham, Massachusetts, has been a leadership volunteer for the New England Chapter of the Society for more than 23 years. He's been a national presence as well, serving as a member of the National Board of Directors since 1988 and as the chair from 1998–2001. He has generated more than $3 million in personal donations and solicitations to fight MS. The study named for his mother honors her memory and promises better lives for everyone who contends with the devastating effects of MS.