Promises Made Promises Kept

Promise: 2010

In November of 2004, the Society made a bold promise: Beginning in 2005, we would raise $32 million over five years to support four research initiatives.

Promise: 2010 proved to be a challenge and an inspiration—a promise that is not only being kept, but one that has profoundly impacted MS research as it moves forward.

The MS Lesion Project

Because people with MS experience the disease in so many different ways, most MS investigators question whether a single therapy will be found to work for all. Understanding patterns of MS damage in **lesions**—spots of brain tissue where myelin has been stripped from nerve fibers—is the focus of the path-breaking international collaboration known as the MS Lesion Project.

Claudia F. Lucchinetti, MD, with collaborators in the U.S., Germany and Austria, launched the most extensive attempt ever to map and understand the meaning of MS damage in the brain. They amassed an unprecedented collection of tissue samples from more than 1,000 people with MS, obtained from brain biopsies (a rare procedure) or autopsies. By identifying four distinct kinds of lesion patterns, the collaborators have:

- changed the way researchers think about MS
- discovered that unique antibody patterns are associated with different lesion patterns, which could lead to a blood test to help inform treatment decisions
- made significant gains in understanding when lesions form and how tissue is damaged, opening up new possibilities for strategies to stop that damage.

An additional grant from the National Institutes of Health is making it possible for these investigators to continue making discoveries about variations in MS that may ultimately drive treatment decisions and increase our understanding of the cause of MS.

Nervous System Repair and Protection

A cure for MS means not just stopping the disease but repairing damage and restoring lost function. Promise: 2010 provided the largest grants in Society history to launch an international effort to address this need. More than 70 leading researchers in four teams in the U.S. and Europe have:

PROMISE 2010
FUNDING VITAL MS RESEARCH

- made progress developing cell transplantation techniques, which may ultimately enable nervous system repair
- developed better imaging methods to track the success of attempts at repair and protection in clinical trials
- successfully induced "stalled" myelin-making cells in lab dishes to begin producing myelin using molecules that have potential as future therapies
- advanced knowledge for further research into repair and protection by publishing more than 150 research papers on nervous system repair in MS.

Because of this targeted progress, the stage is now set for clinical trials of nerve-protecting drugs and for advanced studies of cell transplantation and other strategies for stimulating repair in MS.

Pediatric MS Centers of Excellence

Some 8,000–10,000 children have MS. Another 10,000–15,000 experience what may be MS symptoms. See pages 20–30 for our feature on pediatric MS.

With Promise: 2010 funding, the Society established the first-of-its-kind network of six Pediatric MS Centers of Excellence to provide comprehensive evaluation and care to children with MS and related central nervous system demyelinating disorders. To date the members have:

- provided multidisciplinary care to more than 1,150 kids and their families
- developed consensus on how to diagnose and care for kids with MS
- developed specialized programs and resources for kids, parents, school personnel and heath-care professionals.

Now the way is clear for deeper research into the triggers of MS in young children, which may clarify the cause of MS in adults as well. Children and their families will continue to receive expert care in these six centers.

KEEP THE PROMISE ALIVE

In five short years, significant progress has been made in understanding MS and advancing treatments. There's still time to be part of the Promise: 2010 achievements and support the ongoing work that has been spurred by this benchmark campaign. Your support will help ensure that the next five years will advance as rapidly as the last. Contact your chapter at 1-800-344-4867 today and find out how you can keep the promise alive.

The Sonya Slifka Longitudinal MS Study

The first of its kind in the U.S., this study follows 2,000 Americans with MS. Overseen by Sarah Minden, MD, the study integrates clinical information, health-care practices and socio-economic data to track what happens to people living with MS over time. The study name honors the mother of long-time leadership volunteer Richard Slifka, for her valiant battle with MS.

Findings to date are enhancing the Society's advocacy, research and treatment efforts. Data from the study have:

- been used by the Social Security Administration in preparation for the introduction of the Medicare Part D prescription drug benefit, enhancing access to MS therapies
- helped in the passage of state legislation, resulting in better health care and assistance for severely disabled people with MS
- been used to understand unmet needs of people with MS and new initiatives—such as outreach to enhance community-based care for those living with the disease
- been used to help plan future initiatives of the Society.

Today, the study has entered its second phase with an entirely new sample of almost 2,500 persons with MS who will be followed annually. In order to more accurately reflect the MS population, the study recruited more African-Americans, Hispanics, recently diagnosed, and 18–24 year olds. ■