affects about 140,000 people in the United States (about 40% of the total MS population).

In 1994, Biogen Inc. of Cambridge, Massachusetts introduced its genetically engineered form of beta interferon, which has proven effective in U.S. and European trials in delaying by 75% the average time a patient becomes disabled over a two-year period. Biogen filed with the FDA for approval of Avonex in May 1995. Teva Pharmaceuticals of Israel has also introduced a drug, copolymer-1, which significantly slowed the immune system's attack in human trials. Patients may benefit from a combination of these drugs in their treatment, since they work differently.

But, Kevorkian's victims, no matter how much daily assistance they needed, could have accessed the enormous resources of either the Living and Learning Center in Lansing, Michigan, which helps anyone of any age with any disability (even if they are so incapacitated that they can control only *one* muscle in their body) to vocalize full sentences and to write using commercially available augmentative communication devices; or, Michigan's Alliance for Technology Access, which has 3,500 adaptive devices that zip zippers, adapt personal computers with oversized monitors, and offer free software and hardware options to enlarge texts and increase contrast to allow the legally blind (as was one of Dr. Death's MS victims) to read and type.

## Living with Lou Gehrig's disease

Such adaptive or assistive devices are often basic tools for individuals with amyotrophic lateral sclerosis, or Lou Gehrig's disease. ALS is a neuromuscular degenerative disease in which the nerves supplying the muscles break down, causing a wasting of the muscles in the hands, arms, and legs. But, Kevorkian provided a different "treatment" for four of his victims who had ALS: **Marguerite Tate,** murdered Dec. 15, 1992, died depressed and estranged from her family; **Thomas Hyde,** murdered Aug. 4, 1993, "just gave up"; **Merian Ruth Frederick** was murdered Oct. 22, 1993; and **Nicholas John Loving** was murdered May 12, 1995.

While there is no cure for ALS, results from the largest-ever Phase III trial indicate that Rilutek (riluzole) is the first compound to prolong survival since the disease was first described in 1869. The trial was a multinational study conducted at 31 sites in Europe and North America. Enrollment began in December 1992, with Phase II trials conducted earlier—within a timeframe that could have included Kevorkian's victims. The FDA is now reviewing the application of Rhone-Poulenc Rorer, creator of Rilutek, for treatment IND, usually a 30-day process.

On June 12, 1995, Cephalon, Inc. announced a Phase III clinical trial in which a new therapy, Myotrophin, demonstrated less disease severity, 25% less deterioration, slower progression of the disease, and better functional ability in ALS patients receiving the drug than patients receiving a placebo. Myotrophin, a recombinant human Insulin-like Growth Factor-1 or IGF-1, alters the course of this devastating disease. IGF-1 is a naturally occurring protein found in muscle and tissue, which mediates regeneration of the

## The Passy-Muir valve

Patients who need long-term ventilator support or a tracheostomy undergo a surgical procedure called a tracheotomy, in which a small opening is made through the neck into the windpipe, just below the larynx or voice box. A tracheal tube is inserted, keeping the tracheostomy open and allowing a ventilator link-up. The ventilator pumps air directly in and out of the windpipe. Tracheostomies may be performed for medical reasons other than ventilator support. But, in either case, because the air bypasses the nose, mouth, and vocal cords, the individual can no longer make a sound.

The Passy-Muir one-way valve allows air to be inhaled through the tracheostomy, but closes once air is inhaled. The trapped air is forced up through the vocal cords and nasal passages, allowing the person to speak as the air is exhaled through the larynx.

The tiny (and cheap!) one-way valve has helped thousands of people with brainstem damage; spinal cord injuries; chronic obstructive pulmonary and cardiac diseases; neuromuscular diseases that cause respiratory paralysis, like muscular dystrophy; Guillain-Barré syndrome; poliomyelitis; ALS, or Lou Gehrig's disease; and musculoskeletal diseases or damage.

Not only has the Passy-Muir valve allowed communication so critical during therapy after a stroke or accident, but it also assures that children as young as two months don't skip their pre-speech vocalizing and crucial speech development. Children whose medical condition warrants a tracheostomy or ventilator are now able to participate at school. Since the patient's ability to swallow, to smell, and to taste food improves with the Passy-Muir valve, so does the appetite, thus allowing often-needed weight gain. The one-way valve improves ventilation, as well as the patient's overall health.

David Muir, inventor of the Passy-Muir valve and one of the longest-surviving muscular dystrophy patients, died in 1990, at the age of 28. (Contact: Passy-Muir, Inc., Irvine, Calif., 1-800-634-5397.)