

## Guest Editorial

### Continued commitment to cutting-edge research benefits patients today

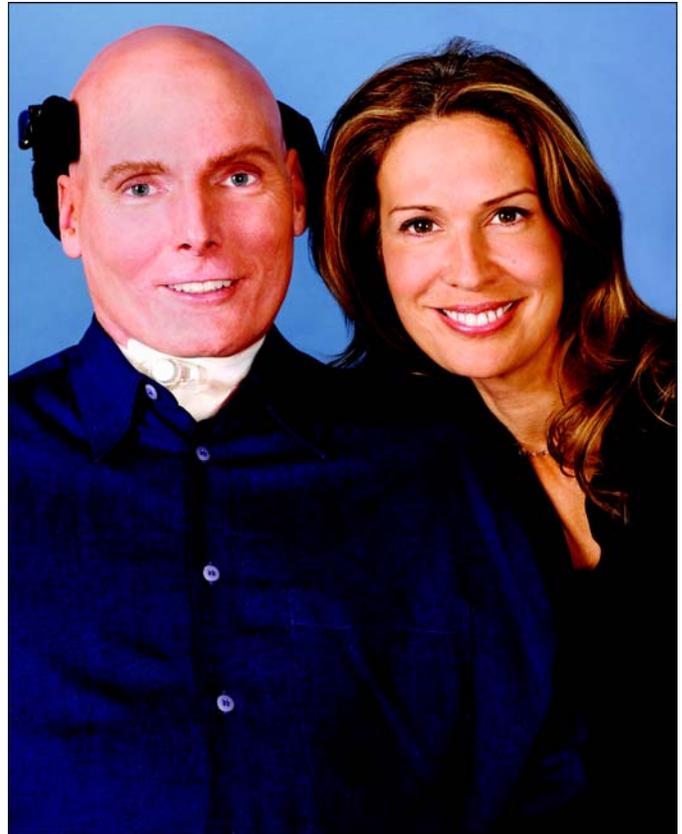
In February 2003, I became only the second patient in the United States to successfully undergo an investigational outpatient procedure designed to help severely spinal cord injured patients like myself breathe without the assistance of a ventilator. The surgery is an exciting example of the promise research holds for patients with spinal cord injury, and highlights the essential role research plays in improving the lives of all people living with paralysis.

During the procedure, surgeons laparoscopically implanted electrodes in both diaphragms near the phrenic nerves that control diaphragm contraction. The electrodes are powered by a small external battery pack attached to wires under my skin; the electrodes cause my diaphragm to contract, thereby allowing my lungs to draw in air and the respiratory system to function normally.

The operation to implant the diaphragm pacing system took just two and a half hours and was minimally invasive. The laparoscopic procedure is significantly safer and less expensive than the standard procedure, which (1) requires surgeons to make large incisions in the chest in order to place electrodes in direct contact with the phrenic nerves, (2) requires a prolonged hospital stay, and (3) costs more than \$100,000; the new diaphragm pacing surgery costs a fraction of that amount and is reversible.

The foundation for the diaphragm pacing system was laid in the 1970s and was nurtured over the years with support from the Department of Veterans Affairs (VA) and other federal agencies in partnership with engineering and medical schools.

The procedure's long history highlights the need for continued, consistent support for research. Recently, the Christopher Reeve Paralysis Foundation proposed first-of-its-kind federal legislation calling for new funding to advance research, rehabilitation, and quality-of-life programs that will benefit persons living with paralysis, their caregivers, and their families.



Christopher and Dana Reeve

If enacted, the Christopher Reeve Paralysis Act of 2003 would—

- authorize additional funding for paralysis research at the National Institutes of Health through the establishment of grants to a consortium of research centers;
- establish a Paralysis Clinical Trials Network through the National Center for Medical Rehabilitation Research;
- call for the Centers for Disease Control and Prevention to carry out projects and interventions focusing on caregiver education, physical activity, and prevention of secondary complications; and
- expand basic rehabilitation and health sciences research at the VA, including a Paralysis

Research, Education, and Clinical Care Center and Consortium to focus on basic biomedical research, rehabilitation research, health services, and clinical trials.

Additionally, the Christopher Reeve Paralysis Foundation continues to fund research into neuroprotection, growth inhibition, promotion of axonal regeneration, and other areas of research that will help in the understanding of spinal cord injury and drive the various approaches toward a cure.

The diaphragm pacing system, which the Food and Drug Administration has approved for testing, offers significant quality-of-life improvements for spinal cord injured patients, including more normal breathing and speaking and improved sense of smell. It also strengthens and maintains the muscle mass of the diaphragms and may lead to the recovery of autonomic breathing.

After my injury eight years ago, I vowed that I would walk again. The road to recovery has been slow, but I see improvements each and every day. Being able to breathe on my own is an important step toward reaching my goal, and I am gratified by

other patients' reaction to the procedure. Encouraged by the success of my surgery and training, 96 patients have enrolled on the waiting list. One individual, a tetraplegic with an injury similar to mine, received the diaphragm pacing system three years ago and has been breathing without the need for mechanical ventilation for more than two years.

Our nation stands on the brink of amazing scientific breakthroughs in treating disorders of the brain and central nervous system. Just as today's diaphragm pacing system is the result of years of earlier research, imagine the treatments and therapies that will be developed by research being conducted now. Federal funding for research has never been more important. We at the Christopher Reeve Paralysis Foundation will continue to do everything we can to ensure that our government increases and maintains its commitment to improving the lives of millions of our fellow citizens.

***Christopher Reeve***

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