

## CurePSP – Society for Progressive Supranuclear Palsy

Since its founding in 1990, CurePSP has provided thousands of patients, caregivers and healthcare professionals with support and education on PSP. Its mission has always been to raise awareness of PSP, advance research toward a cure, educate health professionals and provide support, education and hope for persons with PSP and their families. CurePSP is a lifeline to people who would otherwise be alone and without support. Since 1997, CurePSP has also funded 85 research grants totaling more than \$3.3 million.

### Support for patients and families

Support groups or support networks provide great value to PSP patients and their loved ones. Patients and caregivers can exchange ideas on ways to cope with the physical and psychological limitations of PSP and can learn about problems and treatments from healthcare professionals such as physical therapists, speech and language pathologists, and occupational therapists. Medical centers that have a Parkinson's disease (PD) support group or Movement Disorder Center often welcome members with PSP. You may contact CurePSP for help in finding a support group.

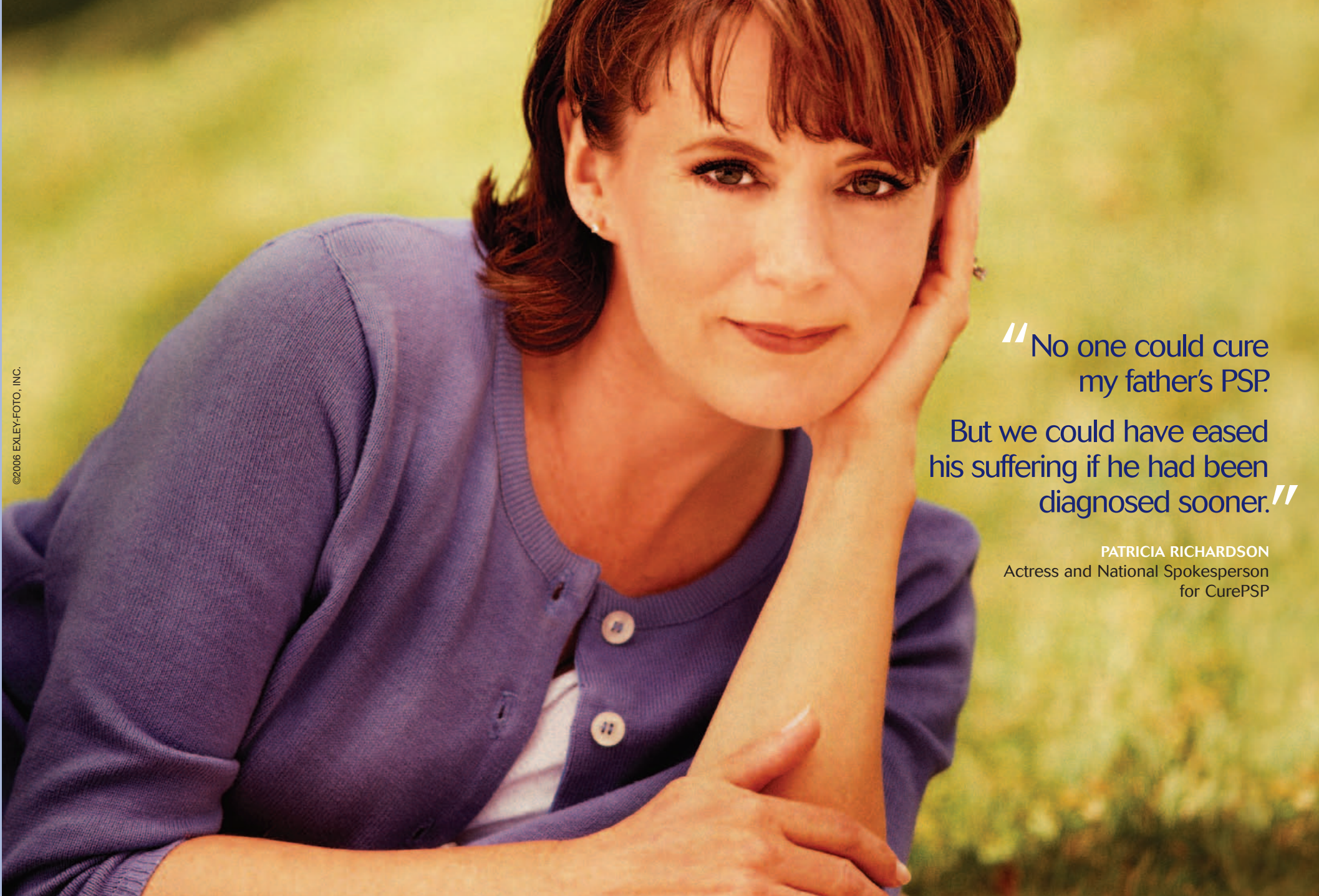
### Further information about PSP and CurePSP is available at:

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**CurePSP**  
Society for Progressive Supranuclear Palsy



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“No one could cure my father's PSP.

But we could have eased his suffering if he had been diagnosed sooner.”

PATRICIA RICHARDSON  
Actress and National Spokesperson for CurePSP

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“My father never fully understood the disease that was slowly taking his life—and neither did we at first.”

**PATRICIA RICHARDSON**  
Actress and National Spokesperson for CurePSP

*Patricia Richardson*

My father, Laurence was an intelligent, proud, funny, robust, active, and athletic man with many types of arthritic injuries and health problems that disguised the onslaught of Progressive Supranuclear Palsy (PSP). Still, he was a tiger. In fact, he was the one taking care of my mom when she was in declining health.

At one point, we noticed that dad was falling a lot. We thought it was mom pulling him down, but it was the other way around. The areas of the brain that were affected most caused increasing damage to his motor skills.

My dad’s disease was gradual, but it progressed steadily toward the end. I found this so sad and wondered why dad deserved this kind of suffering. In his final days, my sisters and I slept in dad’s room and stayed with him around the clock. We petted his brow and held his hand. We played guitar music for him as he had done for us as children. We talked to him, gave him permission to go, laughed and cried, prayed and waited.

It was only after he died that his disease was confirmed. So few people have even heard of PSP. And now I want to do everything I can to prevent others from undue suffering.

## What is Progressive Supranuclear Palsy (PSP)?

PSP is a fatal neurodegenerative brain disease. It affects nerve cells that control walking, balance, mobility, vision, speech, and swallowing. Five to six people per 100,000 will develop PSP, a number similar to that of ALS—amyotrophic lateral sclerosis (Lou Gehrig’s disease). Symptoms begin, on average, when an individual is in the early 60s, but may start as early as in the 40s. It is slightly more common in men than women, but PSP has no known geographical, occupational or racial preference.

## What are the symptoms of PSP?

PSP displays a wide range of symptoms:

- ▲ Loss of balance
- ▲ Changes in personality such as a loss of interest in ordinary pleasurable activities or increased irritability
- ▲ Weakness of eye movements, especially in the downward directions— Later, there is often difficulty controlling the eyelids, producing a wide-eyed stare and poor blinking, resulting in dry and irritated eyes.
- ▲ Weakened movements of the mouth, tongue, and throat
- ▲ Slurred speech
- ▲ Difficulty swallowing—The inability of throat muscles to create a watertight seal outside the patient’s lungs often results in aspiration pneumonia—the most common cause of death in PSP patients.

## What causes PSP?

PSP is caused by a gradual deterioration and death of brain cells in an important place in the base of the brain.

## Is PSP genetic or hereditary?

PSP very rarely runs in families. Less than one in 100 persons with PSP knows of even one other family member with PSP. However, a specific gene irregularity is more common in PSP patients than in the rest of the population. About 95% of people with PSP have this gene variant.

## Why is PSP often confused with Parkinson’s?

Both PSP and Parkinson’s disease cause stiffness, slowness, and clumsiness, a combination called parkinsonism. This is why PSP may be difficult to distinguish from Parkinson’s disease in the early stages. In PSP, there is also severe damage to certain brain cells which remain intact in Parkinson’s. Medications that may be effective for Parkinson’s disease are unfortunately of much less benefit in PSP.

## Does PSP lead to dementia like that in Alzheimer’s disease?

Although mental confusion in patients with PSP is common, most patients do eventually develop some degree of mental impairment. Some are mislabeled as having Alzheimer’s disease. This is similar to the situation in Parkinson’s disease. In PSP, dementia is characterized by slowed thought and difficulty in putting together several different ideas into a new idea or plan. People with PSP also seem to lose interest in their surroundings, creating the impression of loss of thinking ability.

## Is there treatment for PSP?

PSP currently has no effective treatment or medication, although some drugs may have a temporary or modest benefit.

## What research is being done?

Research is proceeding in the areas of genetics, epidemiology, clinical trials, and molecular studies:

- ▲ CurePSP is developing the *PSP Genetics Program*, which will search the entire genome for genes related to PSP and identify biochemical pathways which will target therapeutic interventions.
- ▲ CurePSP is working with the University of Louisville, Movement Disorder Program to study environmental, occupational, and genetic risk factors associated with PSP.
- ▲ CurePSP holds an annual international research symposium attended by scientists, researchers, and physicians from around the world to share their findings and discuss new research.

## What can I do today to support PSP research?

There are several ways you can help:

- ▲ Financial support to fund research is the most obvious way. Grants for PSP research go to both senior researchers and junior researchers with new and original ideas. CurePSP will accept your donation and direct it to the most appropriate research project.
- ▲ If you have PSP, another way to help is to participate in clinical research. This may take the form of answering questionnaires, taking medical exams, or experimental medication.
- ▲ Another important way to help PSP research is to donate your brain after death. Donated brains are stored and used only for research in PSP by legitimate researchers whose proposals are approved by CurePSP’s Scientific Advisory Board.