



## **PRESIDENT-CEO'S UPDATE**

*May 15, 2009*

### *Mission Expansion and How Your Support Will be Used*

After my last update, we received a few very good questions about how the mission expansion will affect donation use by *CurePSP+*. Here's the question:

*"As one contributor and caregiver, my concern is that we are spreading our resources (dollars, people, focus) to widely. Where will my dollars be spent?"*

For many years, *CurePSP* has been serving people with PSP-related disorders as well as atypical Parkinson disorders. These diseases include corticobasal degeneration (CBD) as well as multiple system atrophy (MSA). Because these related disorders are so very similar to PSP in many ways, either in their disease etiology (how the disorders originate in the body) or in their overt symptoms, we have always felt that individuals suffering with these diseases could benefit from our services. In fact, many individuals who have had a clinical diagnosis of PSP actually were found to have (through autopsy pathology) another disorder such as CBD, MSA, or even Lewy Body Parkinson's. At the molecular level in brain both PSP and CBD are very similar and may even be the same disease except that each affects a different part of the brain thus causing different types of symptoms. MSA, while not a tauopathy in the same way as PSP and CBD, express some outward symptoms similar to PSP. Consequently, we have felt that the research and services that we already provide could also benefit those patients and caregivers dealing with these related disorders.

Another benefit of adding these disorders is the ability to reach a larger population of people with neurodegenerative brain disease and better informing the general public about these terrible disorders. The result, we hope, will be more people informed and more support for research, education, and outreach. It is especially true in research that new developments in one disorder often have positive effects in other closely related diseases. Therefore, when there is a breakthrough in one it may also impact another.

At present, our "research mission" includes PSP, CBD and a few extremely rare disorders. While MSA is a significant disease affecting a population very similar to PSP we are not expanding our research mission to include it because it is not a "pure tauopathy". Our research program is very focused in the area of "tau protein processing and genetics." It will only be officially added to our "outreach & education" mission. In these days of economic downturn and very tight budgets, we must try to provide more services and coordinate programs in addition to getting the word out (to

the public and to healthcare professionals) about PSP and its related disorders.

*A metaphor might be fishing boats in a lake that's starved of water because of a dam upstream. If there's only one boat (PSP), its owner may not be able to get the dam authority to open up the sluices much. But if there are multiple boats on the same lake (including some yachts owned by wealthy people), their owners' concerted influence on the dam authority would get better, faster results. All the boats will be floated at the same time, and the PSP boat will be floated faster than it would have been yelling alone.*

How will your dollar be spent? During 2009, if you provide *CurePSP+* with an unrestricted gift it will go to support education, outreach, advocacy, and support for both patients and caregivers. If you make a restricted research gift it will go to fund our Genetics Program or one of our “investigator-initiated research projects” in PSP or CBD. A donor always has the option to designate a gift for a specific purpose or project.

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President/CEO