Getting Social Security Benefits for
Patients with Progressive Supranuclear Palsy (PSP)

by Bruce G. Zimmerman

Social Security disability benefits are provided through the Social Security Administration (SSA). Unfortunately, PSP sufferers have had great difficulty slogging through the system. I have heard of many cases of initial denials and the need for time-consuming and challenging appeals. Part of the problem is that the disease is not well-known and nowhere in the thousands of pages of SSA regulations is there even a mention of PSP. Nevertheless, the benefits of obtaining a disability designation are significant: (a) disability payments are payable monthly effective five months after the deemed full disability date and (b) the disabled person is entitled to the commencement of Medicare benefits twenty-four months thereafter.

This article outlines a strategy to avoid delay, save attorneys' fees and gain approval at the outset of the application process. The key is careful planning and effort, creatively managing the paperwork before submitting.

The various SSA disability application forms are available online at *www.ssa.gov*. I recommend completing the main application form online over several sittings. Rather than thinking about merely completing the bare essentials, take the opportunity to paint a picture of your case by completing the optional portions of the form that allow for commentary regarding particular symptoms that limit one's ability to work. You can save your work online and return to where you left off. The key is to show that, not only can the applicant not do what he/she used to do in very specific, concrete terms but that, effectively, there is no work that the applicant could do. For example, if one was an office worker and now cannot effectively see the keyboard, cannot carry anything because a walker is necessary, and cognitive skills are impaired, how can that person go back to work?

Obtain a copy of *Nolo's Guide to Social Security Disability—Getting & Keeping Your Benefits* by David A. Morton III, MD, Fourth Edition, 2008 (*www.nolo.com*). The book includes a Windows- and Mac-compatible CD which details all the medical disabilities that make one eligible for disability payments. Since PSP is not mentioned specifically, the official "Listing of Impairments" or Blue Book the SSA uses in disability claims (available at *www.ssa.gov*) needs to be reviewed and analyzed. This is critically important and the key to winning at the outset. What is needed is a creative, diligent analysis of the applicable sections of the Blue Book and convincing argument demonstrating that the particularized symptoms of PSP meet the SSA's criteria. Personally, I see it as a persuasive letter integrating the specific medical conditions with the SSA's governing legal framework.

Taking such initiative requires a great deal of careful effort, but I found it very worthwhile. Merely allowing the SSA's determination to ride on the SSA's evaluation of the applicant's medical records and disability application is a mistake. Instead, provide the SSA with an original letter from the applicant's doctor clearly demonstrating how the applicant's PSP

symptoms and the nature of PSP itself meet the SSA's own criteria for a favorable ruling. Presenting such a complete file upfront potentially saves many months of subsequent negotiation and appeal.

As a result of talking to doctors, lawyers and other claimants, I spent weeks preparing a 5-page letter in Word format designed to be edited and sent to the SSA from the applicant's lead doctor. Concurrent with the publishing of this article by CurePSP, this letter will be downloadable from the CurePSP.org website. In addition, a "Symptoms List" document will also be downloadable but is by no means all-inclusive. The idea of the Symptoms List is to help the applicant recall symptoms and generate descriptive language which might be incorporated into the applicant's symptoms section of the letter. Refer also to your doctor's progress notes and to Dr. Lawrence I. Golbe's "Progressive Supranuclear Palsy Rating Scale" available on the CurePSP web site (www.curepsp.org). It is suggested that the letter be prepared in draft form and given to the doctor electronically for review and final editing.

The draft physician's letter to the SSA contains three sections:

1) Background on this little-known disease and some projection of life expectancy. Attorneys that have prevailed on appeal claim that the SSA wants to know life expectancy. It may be that if the disease is very rare and life expectancy is relatively short—and particularly if the patient is older—benefit payments will be limited.

2) The patient's specific symptoms. An example is included in the second section of the letter but should be carefully edited to comply with the applicant's unique set of symptoms and limitations.

3) The third section, "Disability Guidelines and Application" addresses how the specific symptoms of PSP meet the SSA's specific guidelines for permanent disability.

Thus, for the person suffering PSP alone, the form letter has been designed such that only the second section will need to be extensively edited. So, instead of merely relying on the SSA to come to its own conclusion based on its review of the applicant's medical records, the letter's goal is to lead the reader to the conclusion that PSP and the applicant's specific symptoms compel an immediate finding of long-term disability.

A word of caution: I am not a practicing lawyer and this is not my field of expertise. But, concerned from stories of other applicants that SSA approval could take many months or even years, my wife was found permanently disabled within about two weeks of submission of the SSA application accompanied by my doctor letter—without additional medical records other than this single letter from my wife's doctor (who, by the way, is one of the leaders in the field of movement disorders).

Furthermore, even though SSA documentation can be completed over the internet, I recommend hand delivering all initial applicant papers, including this doctor letter, to the SSA office with a copy of each document submitted. The SSA office is used to and will

gladly “date-stamp” each of the filed documents so that you can retain the date-stamped copies for later proof of delivery, if necessary.

PSP is a horrendous disease and it has pained me deeply to hear accounts of those who suffer through the disability claim process or just give up due to the daunting challenges of the SSA bureaucracy. As a dedicated care-giver and advocate for my dear wife who suffers from PSP, my hope is that disability applicants and their doctors will all benefit from using this form letter and the approach outlined in this article.

Bruce G. Zimmerman has an economics degree from Stanford University and practiced law in California in the 1970’s. With the exception of serving as a chain store executive for three years, he was a shopping center developer from 1979 to 1998. For the past 11 years he has been a real estate consultant for major US supermarket chains negotiating new deal structures with landlords of existing supermarkets. He is the author of Shopping Center DealMaker’s Handbook®, a 630-page compendium of electronic form “deal-making” documents for the shopping center industry.

[Use M.D. Letterhead]

[Date]

Social Security Administration
[address]

Re: *Betty Smith*
[insert applicant's address]
SSDI Application #_____
Permanent Impairment: Progressive Supranuclear Palsy

Dear Staff:

[Your doctor should make a brief explanation of his/her expertise, for example:]
My practice is limited to the diagnosis and treatment of movement disorders and I am an active member of a team of doctors conducting the first national study investigating the potential environmental cause(s) of Progressive Supranuclear Palsy.

1. Progressive Supranuclear Palsy—Disease Overview.

Progressive Supranuclear Palsy ("PSP") is a little-known rapidly progressive degenerative brain disease that has no known cause, treatment or cure. The disease eventually causes complete disability by progressively impairing movement, balance, vision, speech and swallowing. PSP patients also typically present alterations in mood and behavior, including depression, anxiety and progressive dementia. The disease was first discovered in 1964 and affects only about 1 out of 100,000 Americans. PSP is only about 1% as common as Parkinson's disease. There is a pressing need to identify the basic mechanisms of abnormal tau accumulation in the brain and to develop appropriate interventional strategies for this relentlessly progressive disease.

Although PSP is referred to as a "Parkinson's Plus" syndrome, it is much more severe and debilitating than Parkinson's disease. While the symptoms of Parkinson's disease can typically be substantially relieved by levodopa/carbidopa, PSP patients generally do not respond to any drug therapy at all. They generally do not benefit at all from levodopa/carbidopa. Further, the characteristic depressed mood, which accompanies PSP, typically does not respond to anti-depressants.

In PSP, most patients eventually require a wheelchair and a feeding tube; speech may become unintelligible, palilalic or mute. In a study of the progression of PSP in patients selected from the research and clinical files of seven medical centers involving tertiary centers of Austria, England, France and the USA, the

median survival time was 5.6 years with a range from 2 to 16.6 years. Pneumonia was the most common immediate cause of death.

In most cases of PSP the visual problem is at least important as the walking difficulty, though it does not appear, on average, until three to five years after the walking problem. Although some patients with PSP describe their symptom as "blurring" or "I can't see", the actual problem is an inability to aim the eyes properly because of weakness or paralysis (palsy) of the muscles that move the eyeballs. Although most other brain problems that affect eye movements originate in nerve cells residing in clusters or "nuclei" near the base of the brain in the brainstem, in PSP, the problem lies in parts of the brain that control those eye-movement nuclei themselves. These "higher" control areas are what the prefix "supra" in "supranuclear" refers to.

A host of visual problems result from the patient not being able to aim the eyes properly. Reading becomes difficult or impossible because the patient finds it difficult or impossible to shift down to the beginning of the next line automatically after reaching the end of the preceding line. Another common problem is an inability to maintain eye contact during conversation. Just observing anything becomes challenging.

2. Betty's Symptoms. *[This section needs to be significantly edited to conform with the particular patient's symptoms. The following text is an example for a particular patient. See separate "Symptom List" for additional ideas.]*

Betty first visited my office on _____, 2008. Even though Betty's balance problems had started five years before and she had experienced some falls resulting in bruising/cuts, it became evident that Betty's long-standing, consistent yoga practice had served to delay the onset of more serious balance interruption. However, she was experiencing the significant eye movement problems characteristic of PSP. I sent her to a renowned neuro-ophthalmologist, _____, M.D., for evaluation of her abnormal eye moments. In _____ of 2009, Dr. _____ confirmed that Betty does, in fact, suffer from PSP.

Since Betty's first visit in _____ of 2008, her condition has dramatically worsened. She cannot walk unaided and uses a walker full-time and has purchased a wheelchair. She permanently stopped driving in _____ of 2009. Limitations in eye movements are more pronounced and she has not worked since _____ (paying bills for her husband's consulting business from her home) because she can no longer see the keyboard and says she no longer has the ability to mentally manage the task. Although, after repeated attempts and effort she can sign her name, she cannot legibly write anything. She finds it very difficult to engage in conversations, sometimes says "yes" when she means "no" and when she is in PSP support group meetings she often "blurts out" comments to the speaker at inappropriate times. She cannot make telephone calls and her husband says there are times when she repeats things as many as five times yet

he cannot understand her. Further, she has lost all affect and strength in her voice and often can't be heard. She is experiencing swallowing problems and frequently coughs while eating, although this feature has not reached the clinically serious stage.

Betty requires full assistance and supervision with activities of daily living (ADLs). Her husband aids her in dressing, bathing and cooks all meals and performs all her former household tasks. It was necessary to hire "live-in" help with her symptoms so a third-party caregiver now assists Betty when her husband is at work. Betty has difficulty eating and swallowing and her husband or caregiver must cut up all her food for her and get her in and out of the table. A special small removable carpet is now used at her place at the table to catch the food that falls around her.

Betty has fallen many times during the past year, resulting in bruising. Because of her eye problems and fear of falling, Betty does not want to go anywhere "new" where she does not know the floor plan, thereby more reliably protecting herself from falling.

3. Disability Guidelines and Application. *[Limited edits should be required for this section. Be careful not to make changes to the text or formatting of sections taken from the Blue Book.]*

Unfortunately, no *specific* reference to PSP as a "listed impairment" appears anywhere in the disability evaluation materials under Social Security. However, there are a number of sections within the Blue Book each of which entitle Betty to a determination of permanent disability. For example, Betty's current symptoms fall squarely within Section 11.17 of the Blue Book:

> [11.17] Degenerative disease not listed elsewhere, such as Huntington's Chorea, Friedreich's ataxia, and spino-cerebellar degeneration. With:
> A. Disorganization of motor function as described in 11.04B; ***or*** [emphasis added]
> B. Chronic brain syndrome. Evaluate under 12.02.

Betty clearly meets the 11.17A. criteria by falling within 11.04B:

> [11.04] B. Significant and persistent disorganization of motor function in two extremities, resulting in sustained disturbance of gross and dexterous movements, ***or*** [emphasis added] gait and station.

Betty cannot walk on either leg without (a) being held by another person or (b) using a specialized, "U-step" walker ("advanced walker" code #EO147). She can no longer write legibly and due to her need to hold onto her U-step walker, another person or other device to keep her upright, effectively she has grossly disturbed dextrous movements. For example, she cannot carry any object from

one place to another. She can hold an electric toothbrush but needs help from her husband or her caregiver putting toothpaste on the brush and cleaning the sink afterwards. She has considerable difficulty in personal hygiene such as combing her hair and taking on and off her hair comb (which keeps her hair from going into her eyes). She cannot dress, undress, bathe or eat without assistance. She can no longer carry out the activities of daily living without the dedicated assistance of another person.

Betty also meets the 11.17B. criteria by meeting the evaluation criteria of Section 12.02:

> [12.02] Organic mental disorders: Psychological or behavioral abnormalities associated with a dysfunction of the brain. History and physical examination or laboratory tests demonstrate the presence of a specific organic factor judged to be etiologically related to the abnormal mental state and loss of previously acquired functional abilities.

The required level of severity for these disorders is met when the requirements in both 12.02A *and* 12.02B are satisfied, *or* when the requirements of 12.02C alone are satisfied.

Betty meets numerous criteria within both A and B (though the regulations require that she merely meet one in each). She also meets multiple criteria within C. Relative to 12.02A, she has "perceptual or thinking disturbances": She is confused, has difficulty managing herself within her environment. Her handwriting is small and illegible and she can no longer use her computer. She has the "change in personality" *and* a "disturbance in mood"; no longer her former outgoing and gregarious self, she is withdrawn, consistently unable to be heard or understood and is depressed and anxious. She now sometimes says "yes" when she means "no", and vice versa. "Impairment in impulse control" is evidenced by her extraordinary difficulty in not interrupting people when they are talking to her, her impatience and her interruptions in public meetings notwithstanding her abnormal "flatness" of demeanor and expression.

Relative to 12.02B, Betty evidences "marked restriction of…activities of daily living…in maintaining social functioning…[*and*] maintaining concentration, persistence or pace."

Relative to 12.02C, Betty has a "medically documented history of a chronic organic mental disorder of at least 2 years' duration (see file notes) that has caused more than a minimal limitation of ability to do basic work activities, with symptoms or signs currently attenuated by medical or psychosocial support", and a "current history of 1 or more years' inability to function outside a highly supportive living arrangement, with an indication of continued need for such an arrangement." She requires and receives assistance regarding all activities of daily living by her care-giver husband and live-in assistant.

It is important to note that there are no treatments to limit, reduce, or stop the relentlessly-progressive, irreversible manner in which PSP causes further and greater limitations in movement of extremities, difficulty with speech and swallowing, and the unique brain-based vision impairment inherent in PSP. Although it is extremely difficult to predict life expectancy for PSP patients, over the years I have managed the medical care for a great many PSP patients and it is my estimate that Betty's life expectancy is in the range of 2 to 4 years.

Section 11.00C's reference to "Persistent disorganization of motor function" is similar to the descriptions of Parkinsonian Syndrome in Section 11.06 and Central Nervous System Vascular Accident in Section 11.04B. All these sections have some similarities to PSP, i.e. significant and persistent disorganization of motor function in at least two extremities which, singly or in combination, result in sustained disturbance of gross and dextrous movements, or gait or station. Further, PSP is functionally analogous to Amyotrophic Lateral Sclerosis (ALS), described in 11.00G, in that it is a progressive, invariably fatal, neurological disease.

To carry the ALS analogy further, individuals with ALS ultimately lose their ability to move their arms and legs, and their capacity to swallow, speak, and breathe. Most people with ALS die from respiratory failure. There currently is no cure for ALS, and most treatments are designed only to relieve symptoms and improve the quality of life.

PSP patients suffer from the same gross deficits as ALS but most people with PSP die of repetitive bouts of pneumonia arising from food aspirating into the lungs due to the patient's inability to swallow properly. Further, while both diseases are neurologically based, ALS is a progressive disease that attacks the nerve cells (motor neurons) responsible for controlling voluntary muscles. In PSP the patient suffers from the deterioration of an area of the brain that not only controls movement, but in addition, controls eye movement, swallowing and autonomic function. The SSA considers a diagnosis of ALS sufficient to allow a finding of disability, *regardless* of how severe the illness.

Thus, in PSP sufferers, in addition to persistent disorganization of motor function analogous to Parkinsonism and ALS, the brain loses the ability to control the sensory input from the eyes. Effectively, PSP sufferers lose the ability to see since areas of the brain that deal with processing visual information are irreversibly damaged. Statutory (legal) blindness qualifies for disability. In short, the advanced PSP patient suffers a "triple-whammy" of (a) persistent disorganization of motor function, (b) disturbance of autonomic function (e.g., swallowing) and (c) significant loss of vision function.

In summary, it is my professional opinion that Betty's PSP symptoms clearly meet both the statutory guidelines for permanent disability and the broad intent

for which the disability regulations were created. This 61-year-old mother, a shadow of her former vigorous self and bearing the brunt of one of humanity's most disabling yet rare diseases, should be declared disabled in an expedited fashion.

Please call me if you have any further questions.

Very truly yours,

_____, M.D.

[Editing note: When all text changes have been made, review carefully and be sure to delete any extraneous text, such as this editorial note. The application and all other SSI documentation should be signed and copied and hand-delivered to your Social Security Disability office. The copy of each delivered document should be "date-stamped" upon delivery and retained by applicant as evidence of submittal.]

Symptom List to Generate Ideas for Paragraph 2 of Doctor's Disability Letter to SSA

[Note: This is by no means a comprehensive listing of PSP symptoms. It is designed to help you think about your symptoms and to help you create your own draft of Paragraph 2 of the letter for subsequent editing by your doctor.]

Eyes

- "Balance was the biggest issue. Now eye focusing is the biggest issue."
- Difficulty moving her eyes.
- Difficulty making eye contact.
- Has to intentionally and incrementally look at a selected object.
- She sees things in increments and occasionally "overshoots"
- Spatial misalignment—For example, she sometimes misjudges distance, such as when walking over to put an object in the trash, she doesn't walk close enough so she then leans over to put the object in the trash.
- Blurred vision at close range. For example, sees 3 eyes on husband's face when he's 18 inches away.
- Difficulty looking up and down. In looking down or up, she sometimes "struggles" (inadvertently looking to the left and right) to see an object directly below or above her. Glasses don't help her reading problems and her neuro-opthalmologist has been unable to fit her with prism glasses that help.
- "Intolerance" to bright lights. In the last few years, eyes have become very sensitive to any kind of light.
- When reading (which she enjoys) she has to be very careful to read the next line; therefore, she uses her finger as a guide. This is a NEW symptom; she has only been reading this way for about 3-5 months. Before that she could easily read the next line down.
- Sometimes she blinks more than she used to and sometimes doesn't blink at all, depending upon how tired she is. She gets dry eye now but eye doctor said that wasn't a big deal (had the test). She thinks she does have dry eyes.
- Sees multiple objects up close. For example, if looks at her husband up close (within one foot to 18 inches, he looks like he has 3 eyes).

Imbalance/difficulty walking

- Loss of balance while walking.
- Walks with wider gate. When we tried "model-style" walking (foot over the other) it was very difficult for her to do it.
- Balance is also "off" when standing.
- Have to "spread my legs out to balance."
- Have had some bad falls, typically falling backwards. She has fallen many times
- Even while being dressed by her caregiver. For example, if the caregiver's hands are putting on her shoes, if Betty falls backwards, the caregiver cannot provide leverage to stop the fall.
- Consistently feels out of balance.
- Always holds spouse's hand or arm when walk together.

- When alone, she's anxious she might fall and is VERY careful so she doesn't fall.
- When walking, sometimes lean to left or right, but this condition occurs mostly at night when getting up to go to the bathroom.
- Difficult navigating going down stairs
- Consistent yoga practitioner but the balancing part has become very difficult — not at all like she used to. Used to just take for granted. Not so now.
- Yoga flexibility has decreased, particularly her neck.
- Pickle ball has become difficult and sometimes misses the ball completely. (When younger she was an outstanding racquetball player.)
- Now generally harder to get out of a chair, particularly a low chair.
- Rigid walk and gate.
- Walks with backs of hands forward with limited arm motion.
- Decreased arm swing.
- Stiffness and awkwardness in gate.

Verbal fluency decline

- Over time her voice has become so soft that she is now very difficult to hear.
- Harder to find the right word—much harder than it used to be.
- Hard to follow people's dialogue, but "could be lack of interest."
- Speech and affect is "flat". Very different voice.
- Generally "less curious" and now more inclined to not care about things.
- Gets confused. Maps and driving directions have become difficult.
- Not as logical and "sharp" as used to be.

Depression

- Took seven different SSRI drugs without benefit.
- Recently started Wellbutrin—some relief but at most nominally helpful.
- Worry about "everything"—that husband might hurt himself doing home chores, family finances, money, health, self-injury during gardening, kids, politics, retirement, etc.
- She continues weekly talk therapy with therapist.

Anxiety

- Generally anxious and much more so than used to be
- Needs to get up and walk around often with her walker (makes her feel better)
- Less able to intervene on immediacy; for example, she wants what she wants when she wants it and tends to be more impatient. She interrupts when speaking to another, yet she never used to do that.

Personality change

- Much, much less expressive and spontaneous.
- Apathetic
- Much less participating in family functions—typically used to call sister and close relatives very often, but no longer does this.
- She says her personality has become "flat"—no ups and downs, "it's just flat."
- Actually, voice has changed, but feels this may be an aspect of personality change.

Fluctuations in cognitive status during the day— Generally starts out good but thinking ability declines as the day goes on; but, sometimes she's really "on" in the afternoon and evening. She sometimes says things that don't make sense and even says "no" when she means "yes".

Sleep disturbance
Not sleeping as well as used to. Tend to wake up very early—5:00 AM sometimes and sometimes wakes up at 3:00 AM but typically falls asleep again.

Mood
- Irritable and tired.
- Fearful
- Social withdrawal—marked change from the past. Used to be "life of the party."
- Wants to stay in familiar home surroundings. Vacation travel is limited to places she has been before and knows the "floor plan". Strange places are uncomfortable and met with anxiety over falling.

Handwriting
Small and cramped style—<u>much</u> smaller and tighter than before and/or her handwriting has become so small and twisted that it is illegible.

Eating/Swallowing
- Needs help with eating because the impairment in her downward gaze makes her unable to see the food on her plate and she is uncoordinated eating.
- She often coughs while eating and needs water to help her swallow her food.

Other
- Now tends to get very hot or very cold—extremes in sense of body temperature.
- Generally tired and used to have high energy.

[Note: The "Progressive Supranuclear Palsy Rating Scale" by PSP's Scientific Advisory Board/Lawrance I. Golbe, M.D., Chair, is available at www.CurePSP.org and serves as an excellent source for symptom analysis and articulation.]