## James Baranski, CEO, National Stroke Association Compassionate Allowance Outreach Hearing Social Security Administration November 18, 2008

- 1.) With regard to the claims of individuals that have had a stroke who unquestionably qualify for disability benefits under SSA's Listing of Impairments, what is your experience or the experience of the people you advocate for in filing for Social Security benefits? Are claims allowed quickly, or do they take longer than anticipated? Is HIPPA an issue?
  - By and large, stroke survivors are frustrated with the length of time to process claims. It is not uncommon to hear survivors complain that the determination period is well beyond 12 months.
- 2.) In those cases where claimants' conditions qualify for benefits and it takes longer than anticipated for claims to be allowed, what do you think are the underlying problems? For example, are there people (including SSA's adjudicators, members of the medical community and others) that are unfamiliar with the various kinds of stroke or how these different conditions impact claimants?
  - Survivors and caregivers often comment about the length of time it takes
    to receive any communication during the adjudication process. Backlogs
    seem to be a frequent problem, leading survivors to question a lack of
    resources available to the SSA.
- 3.) Is obtaining medical evidence a problem? If there are common errors, what are they? Is there a disconnect between the information SSA and state Disability Determination Services (DDSs) needs to allow claims and the kinds of information physicians or other medical providers are accustomed to or comfortable providing about their patients?
  - Unfortunately, depending on where a stroke patient lives, can greatly
    determine their ability to survive a stroke as well as recover/rehabilitation, as
    well as receive appropriate evaluation regarding disability. There is a
    tremendous need to further educate medical providers regarding stroke
    severity and recovery prognosis.
- 4.) SSA currently has processes in place designed to expedite the processing of claims. One process involves terminal illnesses (TERI) cases under the Disability Insurance (DI) program and Supplemental Security Income (SSI) program—and the other involves presumptive disability payments under the SSI program. How are these processes working for individuals who have experienced severe stroke?
  - While the SSA's Quick Disability Determination program is an important step forward to streamline claims processing, we have not yet heard from any of

our 100 plus stroke survivor groups that have experienced an expedited processing of claims. Perhaps this is an area we can focus greater efforts regarding awareness and education to both the survivor and physician communities.

- 5.) With regard to claims that qualify under SSA's current listings, what suggestions do you have for improving the current system for individuals with stroke? For example, would access to a list of the different kinds of stroke including their prognosis and the objective medical evidence needed to establish the conditions be helpful to adjudicators? Can you suggest new ways that medical information pertaining to SSA's functional criteria could help improve the adjudicatory process?
  - The type of stroke is not the issue regarding disability; rather the severity of stroke is most critical as well as other patient comorbidities. Because patients differ greatly in type and timing of stroke, ideally, the evaluation of each stroke patient's recovery would be determined on an individual basis rather than statistical age weighted averages. Recent advances in imaging technologies may make this option a reality in the near future.
- 6.) Please tell us about other suggestions you have about how we can improve our service to individuals with stroke? For example, as we update our neurological and cardiovascular listings, what would you suggest we add to clarify when a stroke is most likely to meet our disability standard?
  - As imaging technologies continue to improve and more is understood about the relationship of stroke severity and plasticity of brain function and recovery, perhaps new standards for disability standards can be established.