

“This ruling sends the message that polio can result in a variety of manifestations in later life that can adversely affect an individual’s ability to function and we (SSA) need to be aware of the cumulative and interactive effects of all of these.”

—Sandra Salan, MD, SSA

New SSA Ruling for Polio Survivors with “Post-Polio Sequelae”

Joan L. Headley, MS, Executive Director, Post-Polio Health International (editor@post-polio.org)

The Social Security Administration (SSA) has issued a new ruling (SSR 03-1p) for evaluating disability claims for polio survivors in the United States seeking Title II SSDI (Social Security Disability Insurance) benefits or Title XVI SSI (Supplemental Security Income) payments.

The new ruling became effective July 2, 2003 upon its publication in the Federal Register. The POMS (Program Operations Manual System), to be released this month, is the document that applies to everyone within the SSA and contains a description of the medical and other evidence that documents the presence of a disabling impairment. SSA will educate the appropriate decision-makers within their system concerning the new POMS.

The new ruling defines post-polio sequelae as the “documented residuals of acute infection as well as all other documented clinical conditions that have an etiological link to either the acute infection or to its residual deficits.”

Motor weakness, usually with muscle atrophy and reduced peripheral reflexes, is listed as the most common residual. Other residuals include post-polio syndrome, degenerative musculoskeletal disorders, early advanced degenerative arthritis, chronic pain disorders, sleep disorders, respiratory insufficiency, and a variety of mental disorders.

Officials at the SSA state that the mental disorders refer to the cognitive limitations some polio survivors have due to revived traumatic psychological experiences associated with acute polio infection, as well as the possibility of a significant psychological effect of

perceiving the onset of further weakness, fatigue, respiratory dysfunction, or joint pain, many years following the acute infection. Signs and symptoms of anxiety and depression may produce further deterioration in function.

The ruling comments that some polio survivors report the onset of problems with attention, concentration, cognition, or behavior. Some researchers have suggested that certain cognitive and behavioral deficits are the result of the prior polio infection that involved the brain, although others do not agree with that concept.

SSA will depend on documentation provided by an individual’s treating physicians and psychologists (including a report of the medical history, physical examination, and available laboratory findings) to establish the presence of post-polio sequelae as a medically determinable impairment.

Other notable facts:

- ◆ Electromyographic (EMG) studies may be used, but are not needed. Typically, SSA will not order or purchase EMG studies.
- ◆ Respiratory insufficiency should be documented by abnormal pulmonary function studies. SSA generally will not purchase a polysomnogram (also called a PSG, sleep study, or sleep test).
- ◆ The careful development of post-polio sequelae should include descriptions of the past acute illness (old records are not required), as well as a report of the current findings on physical examination. The examination report should also include the severity of any residual weakness, as well as

The complete text of the POMS, along with the official identification number, will be on Post-Polio Health International’s website (www.post-polio.org), as soon as possible.

Members without access to the Internet can contact Justine Craig-Meyer (314-543-0475) for a copy.

the onset, pattern, and severity of any new physical or mental deficits.

◆ The medical evidence should readily support an expected duration of at least 12 or more months.

◆ A disability onset date is based on the individual's allegations, his or her work history, and the medical and other evidence concerning impairment severity. Generally, the new problems associated with post-polio sequelae are gradual and non-traumatic, but acute injuries or events may be markers for establishing a disability onset date.

Post-Polio Health International's Medical Advisory Committee assisted SSA in reviewing the proposed document at various stages during the process. The Committee expressed its wish that the medical evidence be inclusive of all of the consequences of having had polio. It also expressed concern about the "mental disorders" terminology. SSA reports that the term does not mean that polio survivors have a mental "impairment" as a result of having had polio and they are not saying "it is all in your head." Nevertheless, they wish to acknowledge that *some* survivors may experience cognitive deficits that result in significant functional limitations even if the cause is unclear.

Lastly, the informal discussions with the SSA staff included the fact that individuals vary in their responses to illnesses and to treatments, and that various treatments used to relieve symptoms can adversely impact an individual's physical and mental functioning, for example, adverse side effects from medications. ●

"The generosity of the participants, and their interest in and appreciation for our work is so important to us – really, it breathes life into all of those numbers."

Claire Kalpakjian, PhD, University of Michigan Medical Center, Ann Arbor

Update on Research Funded by The Research Fund of Post-Polio Health International

(formerly The GINI Research Fund)

Claire Kalpakjian, PhD, University of Michigan Medical Center, reports that 1,200 polio survivors have completed the surveys for the research project – "Women with Polio: Menopause, Late Effects, Life Satisfaction, and Emotional Distress."

The primary objective of the study is to explore the relationship between menopause and late effects for women with a history of polio. Similarly, little is known about the interaction of physical disability and menopause. In an effort to highlight the unique contribution of menopause, men with a history of polio serve as a control group.

Study Finesses Standardized Scale: A standardized scale was developed for a pilot study conducted in the summer of 2002 called the *Late Effects Problems Profile (LEPP)*. This is a scale of 12 commonly reported late effects problems. For each problem, the respondent indicates whether or not this is a current problem (yes/no). If it is, they go on to rate the severity of the problem on a scale of 1 ("slight") to 5 ("extreme"). The total score is the sum of all the severity ratings. In order to evaluate the usefulness of this scale, particularly because it is new and therefore untested, several statistical tests were performed and they suggest that this is a reliable instrument.

Of the 792 participants whose data have been analyzed, their most frequently reported problems from the LEPP were muscle weakness in involved muscles and fatigue (90% and over). Cold intolerance, muscle atrophy, muscle weakness in uninvolved muscles, and muscle pain each were reported in the 70-89% range. Joint pain, sleep problems, contractures, and breathing problems were reported in the 50-69% range.

Kalpakjian (UM-Polio-Research@med.umich.edu) reports that a website dedicated to the project will be established in August.

All study participants will be notified of the website address via a post card. Post-Polio Health International's site – www.post-polio.org – will link to the study site. ●