

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. ●