

Activities of the Post-Polio Program in Johnstown, Pennsylvania

Research

Conemaugh Health System has completed a preliminary outcome study evaluating the benefits of Hatha yoga and meditation in people with post-polio syndrome.

The cardinal characteristic of post-polio syndrome is new onset of weakness that cannot otherwise be explained. Many survivors also experience significant fatigue. It has been shown that mild, less extreme forms of exercise may improve muscular strength and fatigue^{1,2} leading some experts to suggest that the most viable treatment presently available involves management of one's day-to-day activities and non-fatiguing exercise.³

Twenty-three polio survivors, accompanied by their significant others, participated in a five-day retreat in Johnstown, Pennsylvania. The protocol included training in Hatha yoga and mindful meditation, a chronic disease self-management workshop and group support. The participants were then followed for twelve weeks while they utilized a Hatha yoga video specifically developed for this study. Seven outcome measures were used to assess the individuals' responses to the interventions and to compare reliability among the scales used. Participants were assessed at three time periods: baseline (first day of retreat), last day of retreat and twelve weeks after the retreat.

The polio survivors showed significant improvement in areas of fatigue, weakness and pain and continued to practice their skills. At the end of the twelve-week program, individuals averaged

45 minutes of exercise and stress management a day including week-ends. The results of this clinical trial will be used to develop a longitudinal data collection effort integrated with ongoing care and education.

Ongoing research at the John P. Murtha Neuroscience & Pain Institute at Conemaugh Health System includes fatigue issues, osteoporosis and respiratory management.

REFERENCES

1. Einarsson, G. (1991). "Muscle conditioning in late poliomyelitis." *Arch Phys Med Rehabil*, 72, 11-14.
2. Spector, S.A., Patricia, L.G., Yildiz, E., et al. (2001). "Effect of strength training in patients with post-polio syndrome: A preliminary report." *Ann NY Acad Sci*, May 25 1995, 753, 296-302.
3. Dalakas MC. (1999). "Why drugs fail in postpolio syndrome: Lessons from another clinical trial." *Neurology*, 53, 1166-1167.

SOURCE: DeMayo, W., Singh, B., Duryea, B., & Riley, D. (2004). "Hatha yoga and meditation in patients with post-polio syndrome," *Alternative Therapies*, 10(2), 24-25.



Carol Yoder, master trainer and leader of "Healthy Living with a Chronic Condition." Eight classes have been presented as a result of the August 2002 training held in Johnstown. Courses have been offered to polio survivors in Arizona, Florida, Michigan, Oregon and Pennsylvania.



Post-Polio Clinic Directors Meet Monthly on Conference Calls

William M. DeMayo, MD, Director of the Post-Polio Program, moderates monthly conference

calls of Post-Polio Clinic Directors. Past topics include exercise, pain syndromes, bracing and the use of statin drugs in the post-polio population.

During the latter discussion, Dr. Carol Vandenaeker (University of California-Davis Medical Center, Sacramento, California) presented a case study of a polio survivor with high cholesterol, a risk factor for heart disease, who was on Lipitor® (atorvastatin calcium), plus other medications. The survivor reported considerable muscle pain and wanted to determine if it was due to his post-polio syndrome, or to the Lipitor®, which lists new pain and weakness as “serious muscle side effects.”

Dr. Vandenaeker ordered a blood test called a CPK, which measures the amount of creatine phosphokinase in the blood. CPK, an enzyme found predominantly in the heart, brain and skeletal muscle, leaks into the bloodstream when a muscle is damaged, and determining which specific form of CPK is elevated will help determine which tissue has been damaged. The gentleman's CPK was over 500. In the first month off the Lipitor®, his CPK was 327 and finally down to 175. Most importantly, he continued to see his cardiologist and take Zetia® (ezetimibe) to help control his cholesterol.

Ezetimibe is in a class of lipid-lowering compounds that selectively inhibits the intestinal absorption of cholesterol and related phytosterols.

The incorrect information that statin drugs should not be taken by polio survivors continues to be disseminated throughout the polio community. As a result, a number of survivors prescribed statins by their primary physicians to help control their cholesterol refuses to take them.

The Directors recommended that survivors with cardiology risk factors follow their cardiologists' instructions and try the statins while carefully monitoring their symptoms. The Directors acknowledged that an increase in pain and/or weakness could reduce the ability of a survivor to function and thus have an impact on quality of life. They further noted that people are not going to die from muscle pain, but the scientific evidence for the benefits of cholesterol-lowering drugs, including the statins, is significant and taking them can save lives.

The medical literature does not recommend routine monitoring of CPK levels, and none of the Directors routinely check CPK levels in their post-polio patients, but all do use the test when symptoms appear to necessitate it. ●

Post-Polio Clinic Directors who are not receiving the meeting reminders are urged to call Barbara Hull, John P. Murtha Neuroscience & Pain Institute, at 814-269-5232.