The Research Fund Exceeds Half Million; Past Grants Fulfill Aims

The Research Fund of Post-Polio Health International (PHI) surpassed $500,000 in 2006. Begun in 1995 with a generous bequest from polio survivor Thomas Wallace Rogers, Moline, Illinois, The Research Fund continues to grow and allows PHI to fund projects from its earnings that are relevant to the lives of polio survivors. The major aim of The Research Fund is to improve the lives of people with neuromuscular conditions.

Another aim is to provide seed money to talented young researchers as they study unexplored areas and unanswered questions. Claire Kalpakjian, PhD, from the University of Michigan, is an excellent example of that success. Kalpakjian, recipient of PHI’s second $25,000 grant, has had five articles published in peer-reviewed journals related to her research about menopause and women who had polio; several more publications are planned for 2007.

Kalpakjian is in her third year of a $470,000 career development award from the National Center for Medical Rehabilitation Research at the National Institutes of Health. This award supports junior investigators in further training and experience to become principal investigators. Successful awardees typically have some experience independently leading a small study, such as Dr. Kalpakjian did with PHI’s grant. Her current research focuses on menopause in women with spinal cord injury using her previous work in women with post-polio as a springboard.

The third recipient, Noah Lechtzin, MD, MHS, Johns Hopkins University, recently reported on a retrospective study of patients with amyotrophic lateral sclerosis (ALS). It concluded that survival from time of diagnosis was nearly a year longer in the group who started noninvasive positive pressure ventilation (NPPV) use when their forced vital capacity (FVC) was 65% of predicted.

When asked if early use of NPPV could benefit polio survivors, Lechtzin responded, “This is a challenging question. The time to start NPPV in ALS is better defined than in other neuromuscular conditions, but even in ALS it is not clear-cut. My feeling is that until more definitive information is available, this question should be approached clinically.

“I do not think there is any absolute value of FVC or other pulmonary function test that will determine if any individual with post-polio syndrome will benefit from NPPV.

“However, if individuals have shortness of breath (dyspnea), need to sleep sitting up (orthopnea), fatigue, hypersomnia, or difficulty sleeping, NPPV may be beneficial.”

The first award given in 2001 was for a qualitative study of ventilator users’ perspective of life with a ventilator. The final report – “Ventilator Users’ Perspectives on the Important Elements of Health-Related Quality of Life” – is one of the more frequently accessed documents on PHI’s website, www.post-polio.org.