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**P**ost-Polio Health International established its Research Fund in 1995 with a bequest from Thomas Wallace Rogers, a polio survivor and ventilator user from Moline, Illinois. PHI has funded 11 grants over the years. Summaries of the all of the studies, many of which have been published in *Post-Polio Health* and *Ventilator-Assisted Living*, are posted at [www.post-polio.org/res/index.html#awa](http://www.post-polio.org/res/index.html#awa).

The front page article of this issue is a report from the 2014-2015 recipients, represented by lead researcher Antonio Toniolo, MD, Italy. Other recipients reported to PHI recently.

## 2016-2017

The study currently underway with a completion date of late 2017 is entitled, “CoughAssist: use education needs, health service utilization and outcomes.”

Research coordinators, Louise Rose, RN, MN, PhD, Associate Professor, Lawrence S. Bloomberg Faculty of Nursing, University of Toronto, and Mika Nonoyama, PhD, RRT, FCSRT, Assistant Professor at the University of Ontario Institute of Technology and a lecturer in the Department of Physical Therapy at the University of Toronto, Canada, are working with the publically-funded Provincial (Ontario) CoughAssist Program that makes the device and associated equipment available free of charge to ventilator-assisted individuals living at home.

They report that the project is identifying user needs for initial and ongoing education and support for use of the CoughAssist (Philips Respironics) device at home; examining the impact of the Provincial CoughAssist Program on health service utilization, costs and patient-reported outcomes; and exploring user compliance with CoughAssist device prescription.

Nonoyama states, “We have completed interviews for four new users, four new caregivers, five established users and four established caregivers of the CoughAssist device.”

The group is also following new users of the CoughAssist for a nine-month period to collect data on healthcare utilization and costs, patient-reported outcomes and usage. The research coordinator for the project moved to another position, so there has been a delay in recruitment for this part of the study until the job is filled.

## 2013

“Effects of Whole Body Vibration on People with Post-Polio Syndrome,” a study led by Carolyn Da Silva, PT, DSc, Board Certified Neurologic Clinical Specialist, Texas Woman’s University in Houston, Texas, was completed and reported in *Post-Polio Health* (Volume 31, Number 3) Summer 2015.

Fifteen participants (14 with post-polio syndrome, one polio survivor with no PPS) completed a randomized cross-over experimental design study investigating whole body vibration. Each survivor participated in eight sessions within a four-

week period of a low-intensity protocol and eight sessions of a high-intensity protocol, with the order randomized.

Overall, the participants reported significantly less pain severity. The group that started with the higher intensity protocol also walked significantly faster. No significant changes were found in measured leg muscle strength, walking endurance, or self-reported muscle cramping, fatigue, sleep quality or pain interference.

Dissemination of the results included a published abstract with poster presentation at the American Physical Therapy Association Combined Sections Meeting, February 2016 in Anaheim, California. The manuscript is currently under scientific peer review by one journal and has been submitted to another.

Da Silva used this pilot study to help justify a larger federally-funded grant. This study, if approved, will be a home-based whole body vibration study (randomized control trial) of post-menopausal women who are polio or stroke survivors, looking at their bone mineral density, activity levels, pain, etc.

Da Silva adds, “I have also presented the results when training entry-level Doctor of Physical Therapy students, post-professional neurologic clinical physical therapist residents, and physical and occupational therapy staff at local out-patient clinics.”

## 2011

“The Role of Glutathione in Health Outcomes Among Persons with the Late Effects of Poliomyelitis” was completed by a team at the University of Michigan led by Claire Kalpakjian, PhD.

“Essentially, the glutathione intervention had no effect on anything. We concluded that given the high sedentary behavior of survivors in the study efforts may be best served by interventions to increase physical activity,” says Kalpakjian.

The glutathione study has been a challenge for them to publish. It has been rejected twice based on too small a sample and null findings. Twenty people is fine for a pilot study, but there is “not much to take away.”

Kalpakjian reports, “We are trying a third journal, because it is a well-designed little study.” One word of caution from the research team: “We were rejected by one journal because we had published a summary in *Post-Polio Health*.”

Kalpakjian also received PHI funds in 2003 for “Women with Polio: Menopause, Late Effects, Life Satisfaction and Emotional Distress.” That study resulted in two publications: “Quality of Life and Menopause in Women with Physical Disabilities” by Kalpakjian, C., Lequerica, A. in *Journal of Women’s Health*, 2006:15(9):1014-27 and “Hormone replacement therapy and health behavior in postmenopausal polio survivors” by Kalpakjian, C., Riley, B., Quint, E., Tate, D. in *Maturitas*, 2004: 48(4): 398-410.

### Next call for proposals

PHI is scheduled to award its next grant at the end of 2017 for work done in 2018. The deadline to submit a proposal is October 3, 2017. The guidelines and requirements are posted at [www.post-polio.org/res/rfcall.html](http://www.post-polio.org/res/rfcall.html).

### Status of The Research Fund

Funds donated to The Research Fund are sequestered and invested in an account overseen by the Board of Directors of Post-Polio Health International.

As of October 10, 2016, the fund contains \$713,000 of which \$84,000 is committed to projects through the end of 2017.

### Donations appreciated and accepted

Many of the donations come from family members and friends of polio survivors as a tribute to them upon their death. PHI is honored to receive the gifts given out of love and respect for lives well lived.

Donations may be given online at <http://shop.post-polio.org>, a secure area. Gifts may also be mailed to Post-Polio Health International, 4207 Lindell Boulevard, #110, Saint Louis, MO 63108. Please write “Research Fund” on the memo line of the check.

### Final thoughts

I attended the *Australasian-Pacific Post-Polio Conference – Polio: Life Stage Matters*, in Sydney September 20-22. One of my presentations was called “Post-Polio Research: Why and What?” The PowerPoint is online at [www.post-polio.org](http://www.post-polio.org). (If you do not have internet access and would like a copy, contact 314-534-0475.)

The abstracts from the Australasian Post-Polio Conference are in the *Journal of Rehabilitation Medicine* as a PDF and also accessible at [www.post-polio.org](http://www.post-polio.org).

Brian Tiburzi, Post-Polio Health International, also attended and filmed several presentations, including the above-mentioned one, Dr. Toniolo’s update on his team’s research and the presentation, “IVIg as a treatment for post-polio syndrome: trial results,” by Prof. Frans Nollet, MD, PhD, University of Amsterdam, Academic Medical Centre.

They will be posted on [www.polioplacel.org](http://www.polioplacel.org) and shared with Polio Australia for their site, which is scheduled to post the PowerPoints of those presenting who gave their permission. ■