

PRESS RELEASE FROM PHI, November 2000

Research Grant to Examine Ventilator Users' Quality of Life

Post-Polio Health International (formerly Gazette International Networking Institute), awarded its first Research Grant to a multi-disciplinary research team in Toronto, Canada.

The recipients of the \$20,000 award, funded by the Thomas Wallace Rogers Memorial Respiratory Research Grant, seek to expand knowledge about the factors that impact the health and well-being of people with neuromuscular diseases and conditions affecting breathing (polio, ALS, muscular dystrophy, etc.) who live at home with their ventilators.

The study will be conducted through the Clinical Evaluation and Research Unit and the Respiratory Rehabilitation Program at West Park Health Care Centre. Qualitative research methods will be utilized to document long-term ventilator user perspectives on what they consider to be important for the attainment and maintenance of health-related quality of life. In addition, the team will describe how consumers perceive their quality of life changing as personal living circumstances evolve over time and how this relates to independent living. This knowledge can be used to influence service delivery to reflect consumer priorities as well as enhance the system's ability to meet the expectations of long-term ventilator users.

"Even though mechanical ventilation has been available since the polio epidemics of the 1940s, new knowledge about the consequences of long-term ventilation on the quality of life of ventilator users will provide more insight into these individuals' care," stated Martin B. Wice, MD, Medical Director of St. John's Mercy Rehabilitation Center in Saint Louis and President of GINI's Board of Directors.

Members of the research team, led by Mark Tonack, MA, Senior Researcher, Toronto Rehabilitation Institute, and Research Associate, West Park Health Care Centre, are polio survivor and ventilator user Audrey King, MA, Vice Chair, The Center for Independent Living in Toronto; Dina Brooks, PhD, Assistant Professor,

Department of Physical Therapy, University of Toronto, and Research Associate at West Park Health Care Centre; and Roger Goldstein, MD, Professor of Medicine and Physical Therapy, University of Toronto, and Director of Respiratory Medicine, West Park Health Care Centre.

"This study reflects GINI's mission of collaboration among ventilator users, health professionals, and researchers through every phase of the project," says Joan L. Headley, Executive Director, GINI (now PHI). "The outcome promises to provide a crucial link between the ventilator user's perspective and future clinical practice."

Launched in 1995 with a bequest from polio survivor and investment advisor Thomas Wallace Rogers, The Research Fund supports the work of researchers and clinicians investigating the late effects of poliomyelitis or neuromuscular respiratory disease through one of two grants:

- The Thomas Wallace Rogers Memorial Respiratory Research Grant to study the cause and treatment of neuromuscular respiratory insufficiency and the effects of long-term mechanical ventilation;
- The Post-Poliomyelitis Research Grant to study the cause(s), treatment, and management of the late effects of polio.

The grant award is based on a competitive review of proposals by a panel of research experts, health care professionals, and persons with disabilities.

"Tom would be proud that the first grant recipients are exploring home mechanical ventilation," states Oscar A. Schwartz, MD, Tom's physician for many years. "He demonstrated to me that long-term ventilator users live active, involved lives, but there is more to learn." ▲