A $20,000 Health Promotion grant awarded by the Christopher Reeve Foundation (CRF) to Post-Polio Health International will explore and address the problem of inadequate or inappropriate treatment of adult users of home mechanical ventilation in emergency situations.

The outcome will be guidelines for use by ventilator users, their families and advocates, and their health care team to improve the consequences and decisions made during emergency situations.

To date, PHI has developed a project plan, begun collection of all possible persons to be contacted for their experiences relative to this issue, and has planned a February face-to-face session in the Chicago area.

Project leader Virginia Brickley will conduct this meeting with polio survivors who also use a ventilator and their spouses. Linda Bieniek, Mary Ann and Bill Buckingham, and Val and Rick Brew-Parrish will participate in a brainstorming session to assist with the development of the questionnaires designed to capture past experiences, both good and bad.

Members who receive Ventilator-Assisted Living, the quarterly newsletter of International Ventilator Users Network, and names or groups listed in the Resource Directory for Ventilator-Assisted Living will be invited to participate in the collection of experiences via the Internet and mail.

Polio survivors who use a ventilator, their families and/or medical professionals should begin making note of things to share about their experiences in emergency situations. Also, the project will be seeking ideas about what could and should be done differently and where specific change is needed.

The Health Promotion grant, a special category of the CRF Quality of Life grants, is funded through a cooperative agreement with the Centers for Disease Control and Prevention.

The Quality of Life grants program was conceived by Dana Reeve, Chairman of the Christopher Reeve Foundation and Co-Founder of the Christopher and Dana Reeve Paralysis Resource Center, to help people with living with paralysis in the “here and now.”

PHI’s grant was just one of 86 awards given in this cycle totaling $581,034. The CRF also recently gave $100,000 to five Gulf Coast charities in the immediate wake of Hurricane Katrina.

Applications are now being accepted for the 2006 Quality of Life Grants. Deadlines are March 1 and September 1. (www.christopherreeve.org)

Check out www.paralysis.org, the Christopher & Dana Reeve Paralysis Resource Center redesigned Internet site.

If you are a polio survivor who uses a ventilator and does not receive Ventilator-Assisted Living, contact PHI to be involved in this very important work.