To: Members of International Ventilator Users Network  
Fr: Virginia (Ginny) Brickley

I want to keep you informed, through the spring, summer and fall editions of this newsletter, on the progress of the VUME Project—funded by the Christopher Reeve Foundation (CRF)—in which I am privileged to be engaged.

The Motivation: I write this memo with sadness but also with hope. The grant from the CRF was a “Quality of Life” grant, a program conceived by Dana Reeve, who died at age 44 on March 6. May we all exert an extra measure of determination to make this health promotion project a resounding success in her honor.

Project Goal: The project goal is to educate all parties who may be involved in medical emergencies experienced by ventilator users to perform their respective roles with fewer complications, increased confidence and more successful outcomes. “Parties” are users of home mechanical ventilation, their support person(s) and any health care professional they may encounter.

Project Plan: The project’s major steps are to develop a questionnaire for each of the three groups about their emergency experiences; to analyze the responses; and to use the information gleaned to develop specific guidelines for each group.

Questionnaire Development: On February 28, five Chicago-area members shared their medical emergency experiences and lessons learned in a two-hour brainstorming session. The group created a powerful list of issues to use in drafting the three questionnaires. In so doing, Linda Bieniek, Mary Ann and Bill Buckingham, and Valerie and Rick Brew-Parrish also gained a reputation as “the liveliest group we’ve had around here in a while,” according to the director of the Southwest Community Center which hosted us.

Your Turn: By the time this newsletter goes to press, the questionnaires will have been sent to IVUN’s Consumer and Medical Advisory Boards for critique. The VUME Questionnaires will be distributed in early April. But please don’t wait until then to start making note of your experiences. The more thought out and in depth your responses to the questionnaires, the more powerful will be the end product. So we invite you to pick up pen or mouse right away.

While these are certainly not the only questions, the first and most comprehensive questions on each questionnaire are:

What bad experiences have you had during medical emergencies?  
What could have mitigated or eliminated the problem(s)?

What good experiences have you had?  
What contributed to the positive outcome(s)?

Questions?
IVUN’s VUME Project  
c/o Virginia Brickley,  
Project Leader  
146 Geneva Avenue  
Elmhurst, IL  60126  
630-833-0602  
virginia-brickley@comcast.net