

Update on the Ventilator Users' Medical Emergency (VUME) Project

To: IVUN Members

Fr: Virginia (Ginny) Brickley, Leader, VUME Project

GOAL The project's goal is to assist ventilator users, their support persons (personal care attendants, family members and friends) and the health professionals who would treat them to perform their respective roles during a medical emergency with fewer complications, increased confidence, and more successful outcomes.

PROGRESS In May, we distributed questionnaires to ventilator users and their support persons. A steady stream of responses arrived from ventilator users themselves, but not from attendants, family members or support persons.

TRENDS The data in the responses have been amazingly consistent, informative and sobering. Emerging themes include absence of written documentation by users about their condition, medications and equipment; lack of knowledge among health care professionals about neurological conditions and their impact on respiration; and the need for improved access to specialists via the Internet, such as the availability of well-researched comments provided by the late A.E. "Tony" Oppenheimer, MD. Many ventilator users expressed wide-ranging fears about surviving an emergency situation, particularly regarding anesthesia and oxygen use.

NEXT STEP We are now preparing a questionnaire for health care professionals, using the information gained from users and their attendants and family members.

An important part of this step is reaching the many professionals who would interact with ventilator users in an emergency situation (power failure, traffic accident, heart attack, etc.). It is critical that we reach health care professionals who can contribute by describing challenges they face when treating ventilator users and/or by suggesting solutions for those challenges.

We are asking ventilator users to recommend health care professionals to receive the questionnaire designed for them. Contact me with their name(s), address(es) and phone number(s) and advise if we may use your name when contacting them.

If you are such a professional and want to be involved in this project, please contact me or Joan L. Headley at ventinfo@post-polio.org. More details are posted on www.post-polio.org. ▲

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Respiratory Management Following Spinal Cord Injury: A clinical practice guideline for health-care professionals (©2005) contains recommendations for the acute phase of SCI that can also be applicable to anyone with SCI experiencing respiratory problems. Recommendations include prevention and treatment of atelectasis and pneumonia, tracheostomy, PEEP, medications, diaphragmatic pacing, dysphagia and aspiration, psychosocial assessment and discharge planning.

Produced by the Consortium for Spinal Cord Medicine, chaired by Kenneth Parsons, MD, the guideline provides a valuable discussion of weaning from the ventilator and when long-term use is indicated. Clinical protocols from Craig Hospital in Colorado are appended. Available in PDF format (\$3) or hard copy (Publ. #2900-179, \$19.95 plus \$3 shipping/handling) from Paralyzed Veterans of America, 888-860-7244, www.pva.org/pvastore. ▲