

## Take Charge, Not Chances

### A Portfolio for Users of Home Mechanical Ventilation, Their Caregivers and Health Professionals

International Ventilator Users Network, an affiliate of Post-Polio Health International, serves a unique group of people. *Ventilator-Assisted Living*, our quarterly newsletter, is our long-standing method of communicating with you. The best communication is that in which both parties speak and both parties listen.

A few years ago, IVUN began to hear from ventilator users who experienced very distressing hospital stays. Family members reported deaths; ventilator users expressed panic. The task of consoling families and alleviating fear became more prevalent. It never became easier.

A cadre of ventilator users harnessed their fear and looked for a solution; they found part of it, at least, in the Christopher & Dana Reeve Foundation Quality of Life Grants. Spurred on by their vision and able assistance, IVUN applied for a grant to “assist ventilator users, their support persons and health professionals who treat them to perform their respective roles during a medical emergency with fewer complications, increased confidence and more successful outcomes.”

Upon receiving the grant, IVUN surveyed ventilator users and their family members, caregivers and health professionals. We surveyed health professionals with years of experience in home mechanical ventilation and numerous professional organizations that represent health professionals who may interact with ventilator

users during treatment. Lastly, we surveyed the directors of education and patient services of disease-specific organizations for whose members home mechanical ventilation is a possibility.

Project Leader Ginny Brickley collected, organized, analyzed and synthesized the data and then expanded the circle of interviewees until the issues were clearly defined. We then began work on preliminary guidelines to address the major problems facing ventilator users during a medical emergency. Over the next several months and through many evolutions, the product became **Take Charge, Not Chances**, a portfolio of four major documents.

The four documents and ancillary information are printed in this special 20-page edition of *Ventilator-Assisted Living*. The documents are also available at [www.ventusers.org](http://www.ventusers.org).

For IVUN, this portfolio fulfills the grant. But we think there is more to do. The portfolio could be modified slightly to serve children and to serve ventilator users in other countries. The portfolio could be translated into other languages. The information could be developed into a web-based module for training so health professionals who need this kind of information have access to it.

For you as a ventilator user, caregiver or health professional, the time to **Take Charge, Not Chances** is now. ▲

—Joan L. Headley

Special Edition

## The Power of Preparation: A Personal Experience

by Ginny Brickley

While I served International Ventilator Users Network (IVUN) as project leader for the development of the **Take Charge, Not Chances** portfolio, my friend Linda Bieniek\* experienced respiratory failure following surgery unrelated to her post-polio condition.

During five very difficult months of her recovery – including adjustment to a tracheostomy – in two general hospitals, one rehab hospital, and one nursing/rehab facility, I was privileged to be one of Linda's rotating friend-caregivers. Time and time again I witnessed health professionals, caregivers, and especially Linda (who was unable to speak during that time), struggle to understand and/or communicate what was needed. Had the **Take Charge, Not Chances** portfolio been in existence at that time I believe many very serious and frightening moments could have been avoided and recovery expedited.



One example of such a moment is that it took a skilled and caring respiratory therapist in an out-of-state hospital about a week of trial and error to figure out Linda's vent settings which Linda, heavily sedated after surgery, could not communicate. Those settings are now recorded in Linda's **Patient's Vital Information for Medical Staff** document. Further, in her copy of **Treating Neuromuscular Patients Who Use Home Ventilation: Critical Issues**, there is a directive for the hospital respiratory care practitioner to consult with the home respiratory care practitioner, whose phone number is included. And, this is just for starters.

\*Coincidentally, Linda, a Certified Employee Assistance Professional, a former IVUN board member, and a twenty-year ventilator user who now continues her recovery at home, helped write the grant application which led to the Christopher & Dana Reeve Foundation's funding of this project. Her critical event occurred a month after the project began. Thank you, Linda, for your guidance and strength.

Prepared by

**IVUN**  
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Dear User of Home Mechanical Ventilation,

In the spring of 2006, the Ventilator Users' Medical Emergency project of International Ventilator Users Network (IVUN) asked ventilator users with a neuromuscular condition, their families and caregivers, and their health professionals how to improve the often traumatic outcome of medical emergencies. To our surprise, all three groups cited the same three factors as most critical for fostering successful emergency care.

- Advance preparation by ventilator users,
- Open communication between all parties, and
- Education of medical staff about the unique needs of this group.

Thanks to funding from the Christopher & Dana Reeve Foundation, IVUN is pleased to present a portfolio of four documents which address these issues head on. We've called this portfolio "Take Charge, Not Chances."

Now we invite you to do just that! You can take charge by doing the work of making these documents your "own" and by having the last two with you at all times. *You can download the third document and customize it as needed.* The other three are for use "as is," although they may be updated occasionally on IVUN's website ([www.ventusers.org](http://www.ventusers.org)).

To begin, access any of the four documents on IVUN's website, as listed below, or see the enclosed documents.

Document	Responsibility for Action
Home Ventilator User's Emergency Preparation Checklist <a href="http://www.ventusers.org/vume/HomeVentuserChecklist.pdf">www.ventusers.org/vume/HomeVentuserChecklist.pdf</a>	Ventilator User completes it and, if desired, informs IVUN for recognition.
Caregiver's Emergency Preparation Checklist <a href="http://www.ventusers.org/vume/CaregiverChecklist.pdf">www.ventusers.org/vume/CaregiverChecklist.pdf</a>	Caregiver(s) completes it and, if desired, informs IVUN for recognition.
Patient's Vital Information for Medical Staff <a href="http://www.ventusers.org/vume/PatientInfo.pdf">www.ventusers.org/vume/PatientInfo.pdf</a>	Ventilator User completes it for use by Medical Staff.
Treating Neuromuscular Patients Who Use Home Ventilation: Critical Issues <a href="http://www.ventusers.org/vume/TreatingNeuroPatients.pdf">www.ventusers.org/vume/TreatingNeuroPatients.pdf</a>	Ventilator User completes it for use by Medical Staff.

## **A Community Empowered**

While you are working your way through the documents, we invite you to connect electronically with others who are doing the same. You can share a question, problem, solution, success story, or your general musings about your “Take Charge, Not Chances” experience.

To connect, please e-mail us at [info@ventusers.org](mailto:info@ventusers.org). IVUN will post these items on its website along with your contact information, enabling ventilator users worldwide to become a community of persons helping each other to “Take Charge, Not Chances.”

## **Something to Celebrate!**

Finally, we invite you and your caregivers(s) to notify us at [info@ventusers.org](mailto:info@ventusers.org) when you’ve completed your Emergency Preparation Checklists, so that we can recognize you for “Taking Charge.”

There are so many things we cannot change. But we can be prepared for a medical emergency. We believe peace of mind will be the reward.

## ***We look forward to hearing from you.***

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***International Ventilator Users Network’s mission is to enhance the lives and independence of home mechanical ventilator users and polio survivors through education, advocacy, research and networking.***

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*Special thanks ...*  
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***To be sure you receive email updates from PHI and IVUN, set your spam filters to allow messages from [info@post-polio.org](mailto:info@post-polio.org) and [info@ventusers.org](mailto:info@ventusers.org)***



## Home Ventilator User's Emergency Preparation Checklist

***Reminder to Self: No matter how stable my condition or how well I am doing, a good outcome in an emergency depends upon my taking care of business beforehand.***

### Completing My Documents

- 1. I have completed the [Patient's Vital Information for Medical Staff](#) and secured on it the signatures and phone numbers of my primary care physician and pulmonologist.
- 2. I have read and I understand [Treating Neuromuscular Patients Who Use Home Ventilation: Critical Issues](#), the IVUN briefing for health professionals.
- 3. I have given copies of the above documents to my primary care physician and all other health professionals.

### Conversation with My Caregiver(s)

- 4. I have reviewed the [Patient's Vital Information for Medical Staff](#) with my caregiver(s) and given each a copy.
- 5. To facilitate rapid emergency treatment, my caregiver(s) and I have agreed on who will be my main spokesperson in each of several possible emergency scenarios.
- 6. My caregiver(s) and I have talked through what we will do and say in the event of a communication breakdown with health professionals.

### Getting Acquainted with Emergency Personnel

- 7. If my hospital is small, I have introduced myself to the Emergency Department and given them the [Patient's Vital Information for Medical Staff](#) and [Treating Neuromuscular Patients Who Use Home Ventilation: Critical Issues](#). If my hospital is large, I have requested that they upload digital copies of these documents into their file on me.
- 8. If possible, I have had my home ventilator and, if applicable, CoughAssist<sup>®</sup> approved in writing by my local hospital for in-hospital use and have attached the documentation to [Patient's Vital Information for Medical Staff](#).
- 9. If applicable, my caregiver(s) are prepared to administer the CoughAssist<sup>®</sup> in the absence of available respiratory or nursing staff.
- 10. I have given a copy of my [Patient's Vital Information for Medical Staff](#) to my local fire department to alert them to my condition and unique needs.
- 11. I have given a copy of my [Patient's Vital Information for Medical Staff](#) to my local ambulance/paramedic service and, if possible, cleared my equipment with them for use during transport.

## Assuring Backup Power

- 12. I have a backup power supply in my home or one that is readily available to me.
- 13. I have a backup ventilator readily available for use in an emergency.
- 14. I have a manual resuscitator bag at home and carry one with me when I leave home.

## Documenting My Wishes

- 15. To assure that my wishes are respected I have completed a Medical Power of Attorney (*also called Durable Power of Attorney for Health Care*) form authorizing another to make medical decisions if I am unable. If this form does not include a section stating the conditions under which I do/do not want to continue medical care, I have also completed a brief Living Will. (Forms for these two documents may vary by state. Search the Internet and/or contact your local library for state-recommended forms.)
- 16. I have given the above documents to my physician(s), family and caregiver(s).

## Pausing to Consider

- 17. I am aware that in general the pulmonologists most skilled in treating persons who use home ventilation due to a neurological condition are those who treat diseases of the muscles rather than those (many pulmonologists) who treat diseases of the lungs. (Check IVUN website and/or the nearest MDA and/or ALS clinic for these specialists.)
- 18. My caregiver(s) and I are prepared to seek additional expert opinion on the necessity/timing of a tracheostomy, should that procedure be proposed by physicians not familiar with noninvasive ventilation.

## Traveling with Important Documents

- 19. I have assembled the following and always carry the packet with me when I leave home.
  - Patient's Vital Information for Medical Staff
  - Treating Neuromuscular Patients Who Use Home Ventilation: Critical Issues
  - Living Will
  - Medical Power of Attorney
  - Insurance Cards

## Celebrating Success

- 20. I have notified IVUN that I have completed this checklist and would like to be recognized on the IVUN website ([www.ventusers.org](http://www.ventusers.org)) and in its newsletter for this accomplishment.

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## Caregiver's Emergency Preparation Checklist

*For Those Who Assist Persons Using Home Ventilators*

- 1. I have read and understand the [Patient's Vital Information for Medical Staff](#) document which the person I support has completed for use in an emergency.
- 2. The person whom I support and I have talked through his/her [Home Ventilator User's Emergency Preparation Checklist](#) to the satisfaction of both of us.
- 3. I have visited the local hospital's Emergency Department and the local Emergency Medical Services facility with the person whom I support. Or, if the hospital is large and very busy, we have simply requested that they upload the [Patient's Vital Information for Medical Staff and Treating Neuromuscular Patients Who Use Home Ventilation: Critical Issues](#) into their patient records.
- 4. I have read and understand [Treating Neuromuscular Patients Who Use Home Ventilation: Critical Issues](#) written for medical professionals.
- 5. The person whom I support and I have talked through a handful of emergency scenarios, rehearsing who would do and say what in each case.
- 6. I am aware that burnout during a medical crisis of the person I support is a real possibility for me and that a network of support is critical for preventing and/or dealing with this.
- 7. I have listed and discussed with the person I support some of the support that I as a primary caregiver may need during his/her medical emergency.
- 8. The person whom I support and I have made a list of persons who might become part of this network, e.g., a backup caregiver, friends to visit, neighbors for pet care, family to problem solve and make decisions, a counselor to support me.
- 9. To nurture an honest and respectful relationship between us, the person whom I support and I periodically talk about what we need from/can give to each other.
- 10. I have notified IVUN that I've completed this checklist and would like to be recognized on IVUN's website ([www.ventusers.org](http://www.ventusers.org)) and in its newsletter for this accomplishment.

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## Patient's Vital Information for Medical Staff

To be used along with

Treating Neuromuscular Patients Who Use Home Ventilation: Critical Issues

### MY INFORMATION

Patient \_\_\_\_\_ Birth Date \_\_\_\_\_

Medic Alert ID # \_\_\_\_\_

Company Name \_\_\_\_\_

Company Phone \_\_\_\_\_

Neuromuscular condition \_\_\_\_\_ Age at onset \_\_\_\_\_

If trached, age when occurred \_\_\_\_\_ If noninvasive ventilator use, age when began \_\_\_\_\_

Ventilatory assistance is needed \_\_\_\_\_ hr/day and \_\_\_\_\_ hr/night, or \_\_\_\_\_

If scoliosis, degree of curvature \_\_\_\_\_

Health facility of choice when stable \_\_\_\_\_

**Important!** My caregiver(s) and I are extremely knowledgeable about my condition, treatment needs and equipment. Please work with us.

### Authorization to Speak with Caregiver(s)

I need my caregiver(s) to be with me during my entire treatment and I authorize you to consult with my caregiver(s) (family, friend or home health personnel) with no privacy or timeframe restrictions.

Caregiver Name \_\_\_\_\_ Phone \_\_\_\_\_

Caregiver Name \_\_\_\_\_ Phone \_\_\_\_\_

Caregiver Name \_\_\_\_\_ Phone \_\_\_\_\_

Patient Signature \_\_\_\_\_ Date \_\_\_\_\_

### HOW I COMMUNICATE

- Speech
- In writing
- Via speaking device
- Via my caregiver
- With a bell
- Other \_\_\_\_\_

### Important!

- I use noninvasive ventilation.** If intubation or a tracheotomy is proposed, please consult me, my caregiver and my physician listed in the "My Health Professionals" section.
- I have a tracheostomy.** It is critical that you consult me regarding the details of my routine.

Patient \_\_\_\_\_

## MY HEALTH PROFESSIONALS

You have my permission to contact, at any time, these health professionals who have agreed to consult.

### PHYSICIAN #1

Name \_\_\_\_\_ Specialty \_\_\_\_\_

Comments \_\_\_\_\_

Signature \_\_\_\_\_ Phone \_\_\_\_\_ Date \_\_\_\_\_

### PHYSICIAN #2

Name \_\_\_\_\_ Specialty \_\_\_\_\_

Comments \_\_\_\_\_

Signature \_\_\_\_\_ Phone \_\_\_\_\_ Date \_\_\_\_\_

### PHYSICIAN #3

Name \_\_\_\_\_ Specialty \_\_\_\_\_

Comments \_\_\_\_\_

Signature \_\_\_\_\_ Phone \_\_\_\_\_ Date \_\_\_\_\_

### Respiratory Care Practitioner (RCP) – Please direct hospital RCP to consult with this RCP.

Name \_\_\_\_\_ Phone \_\_\_\_\_

Home Health Company \_\_\_\_\_ Phone \_\_\_\_\_

Instructions: \_\_\_\_\_

Signature \_\_\_\_\_ Date \_\_\_\_\_

**For additional specialists available to consult in relation to neuromuscular patients who use ventilators, see last page of this document or go to [www.ventusers.org/net/ventDIR.pdf](http://www.ventusers.org/net/ventDIR.pdf).**

## MY TREATMENT

**OXYGEN:** I require supplemental oxygen  Never  Always  Part Time

### **Caution! Providing oxygen to me may have dire consequences!**

Oxygen used alone may mask or accelerate acute respiratory failure in neuromuscular patients.

The response to low oxygen levels must be to increase ventilatory support and secretion management, NOT simply to administer oxygen.

**Administer oxygen to me ONLY** if all four of these conditions are met.

- I have an additional pulmonary condition such as pneumonia, COPD or pulmonary embolism, **and**
- My O<sub>2</sub> saturation is below 90% **and**
- Secretion management, e.g., CoughAssist® or air stacking, has failed to improve saturation levels **and**
- My mechanical ventilation is securely in place.

Then provide only low levels of oxygen and monitor CO<sub>2</sub> levels. Oximetry and EtCO<sub>2</sub> (End Tidal) are preferable and adequate for measurement.

Patient \_\_\_\_\_

### ANESTHESIA/SEDATION

I must be ventilated before I am given sedation/pain medication.  Yes  No

I can tolerate \_\_\_\_\_

I've had negative reactions to \_\_\_\_\_

**Caution!** Anything that depresses respiratory drive must be used with great caution.

See Treating Neuromuscular Patients Who Use Home Ventilation: Critical Issues.

### MY ALLERGIES

\_\_\_\_\_  
\_\_\_\_\_

### MY TYPICAL VITALS *(These can change during ventilation and position change.)*

Blood Pressure \_\_\_\_\_ Sitting Vital Capacity \_\_\_\_\_ %N \_\_\_\_\_ Oxygen Saturation \_\_\_\_\_

Temperature \_\_\_\_\_ Supine Vital Capacity \_\_\_\_\_ %N \_\_\_\_\_ Carbon Dioxide Level \_\_\_\_\_

Peak Cough Flow \_\_\_\_\_

Other \_\_\_\_\_

### MY POSITIONING

Without ventilatory assistance I am at mortal risk in these positions \_\_\_\_\_

\_\_\_\_\_

My best positions are \_\_\_\_\_

### MY EQUIPMENT

I prefer to use my home equipment. (If applicable, hospital pre-approval is attached.)

If use of home device is not feasible, hospital's equivalent is second best.

### FOR VENTILATION

I require breathing assistance for \_\_\_\_\_ hrs/day and \_\_\_\_\_ hrs/night, or

Other \_\_\_\_\_

### My breathing machines/ventilators include

#1 Type and Model \_\_\_\_\_

Manufacturer \_\_\_\_\_

### Settings

Mode  Assist Control  Pressure Support  SIMV (combination)

Inspiratory Time \_\_\_\_\_ Breathing Effort (BPM) \_\_\_\_\_ PEEP \_\_\_\_\_ Sensitivity \_\_\_\_\_

Low Pressure Limit \_\_\_\_\_ High Pressure Limit \_\_\_\_\_ Alarm: High \_\_\_\_\_ Low \_\_\_\_\_

Tidal Volume \_\_\_\_\_ Rate \_\_\_\_\_ IPAP \_\_\_\_\_ EPAP \_\_\_\_\_

Other \_\_\_\_\_

**Patient** \_\_\_\_\_

#2 Type and Model \_\_\_\_\_

Manufacturer \_\_\_\_\_

**Settings**

Mode  Assist Control  Pressure Support  SIMV (combination)

Inspiratory Time \_\_\_\_\_ Breathing Effort (BPM) \_\_\_\_\_ PEEP \_\_\_\_\_ Sensitivity \_\_\_\_\_

Low Pressure Limit \_\_\_\_\_ High Pressure Limit \_\_\_\_\_ Alarm: High \_\_\_\_\_ Low \_\_\_\_\_

Tidal Volume \_\_\_\_\_ Rate \_\_\_\_\_ IPAP \_\_\_\_\_ EPAP \_\_\_\_\_

Other \_\_\_\_\_

**MY INTERFACE(S) for access to my breathing machine/ventilator include**

Nasal Mask  Nasal Pillows  Trach Tube (See detail below.)

Face Mask  Mouthpiece  Custom-made Mask

Model \_\_\_\_\_ Size \_\_\_\_\_ Manufacturer \_\_\_\_\_

Model \_\_\_\_\_ Size \_\_\_\_\_ Manufacturer \_\_\_\_\_

Model \_\_\_\_\_ Size \_\_\_\_\_ Manufacturer \_\_\_\_\_

**Trach Tube details**

Fenestrated?  Yes  No

Cuffed?  Yes  No If yes, inflation is: Day @ \_\_\_\_\_ cc Night@ \_\_\_\_\_ cc

**FOR HUMIDITY, I use** \_\_\_\_\_

**FOR SECRETION MANAGEMENT, the most effective methods for me are**

CoughAssist® – Inhalation \_\_\_\_\_ Exhalation \_\_\_\_\_ # Breaths \_\_\_\_\_

Suctioning – Depth \_\_\_\_\_ Frequency \_\_\_\_\_ Catheter Size \_\_\_\_\_

Postural Drainage – Method \_\_\_\_\_

Bagging \_\_\_\_\_

Percussor – Locations \_\_\_\_\_ Times/Minutes \_\_\_\_\_

**FOR FEEDING/NUTRITION, I use**

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**MY BOWEL ROUTINE is**

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Patient \_\_\_\_\_

**MY CURRENT MEDICATIONS**

BRAND NAME	GENERIC NAME	Dosage & Frequency	PURPOSE	When Begun	How Long Used	Special Instructions

**This document belongs to**

Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Country \_\_\_\_\_

Email \_\_\_\_\_

Phone \_\_\_\_\_ Fax \_\_\_\_\_

**I have read and approved the contents of this document.**

Ventilator User Signature \_\_\_\_\_ Date \_\_\_\_\_

Witness Signature \_\_\_\_\_ Date \_\_\_\_\_

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## Treating Neuromuscular Patients Who Use Home Ventilation: Critical Issues

This patient, \_\_\_\_\_,

has a neuromuscular condition that requires  invasive  noninvasive home ventilation.

**Take note of these nine issues critical for treatment.**

### 1. The patient and designated caregiver are experts.

Long-term ventilatory support at home requires different skills and knowledge than acute ventilation in an emergency or intensive care unit. Long-term ventilator users frequently have years of experience in dealing with ventilatory issues and respiratory care problems and have learned what works and what does not. They know their bodies and their equipment.

It is not possible for medical providers in acute care settings to know all of the strategies patients have developed to deal with their unique problems. So it is critical for medical providers to approach these patients with an open mind and accept the patient's suggestions *even if they run contrary to standard hospital protocols*. **It is recommended that the attending physician state in the orders that the caregiver should remain at all times to participate in care.**

### 2. Communication is critical to successful treatment.

**So if patient is conscious, please:**

- **Listen.** Read lips/provide paper and pen/utilize patient's communication device if needed.
- **Repeat back** what you hear, providing an opportunity for the patient to clarify.
- **Talk directly to the patient.** A patient unable to communicate may still comprehend. Explain your findings and treatment plan.

### 3. For patients with a pre-existing tracheostomy (the interface for hyperinflation maneuvers and ventilation).

The patient's routine may include less common details such as cuffless ventilation or ventilation with a Passy-Muir™ valve in place. Additionally, serious acute illness may require changes such as temporary use of a different type of trach tube. **Please discuss with patient and caregiver and return to the patient's own routine as soon as possible.**

### 4. **Caution!** Providing oxygen alone may have dire consequences!

Oxygen used alone may mask or accelerate acute respiratory failure in neuromuscular patients. The response to low oxygen levels must be to increase ventilatory support and secretion management, NOT simply to administer oxygen.

**Give oxygen to neuromuscular patients ONLY** if all four of these conditions exist:

1. There is an additional pulmonary condition such as pneumonia, COPD or pulmonary embolism, **and**
2. O<sub>2</sub> saturation is below 90% **and**
3. Secretion management, i.e., CoughAssist® or air stacking, has failed to improve saturation levels **and**
4. Mechanical ventilation is securely in place.

Then provide only low levels of oxygen and monitor CO<sub>2</sub> levels. Oximetry and EtCO<sub>2</sub> (End Tidal) are preferable and adequate for measurement.

**Ventilation is critical.**

Patients with neuromuscular disorders require VENTILATORY support. Unless the neuromuscular patient has a separate pulmonary disease, hypoxemia signals either accumulation of secretions or inadequate ventilation. START VENTILATION AND A SECRETION MANAGEMENT PROGRAM.

- Ventilation can be noninvasive via a mask or mouthpiece or provided by an existing tracheostomy with a machine-set respiratory rate. Intubation may be required temporarily in emergency situations if noninvasive ventilation is not currently effective.
- Secretion management should primarily be hyperinflation using the patient's customary method, i.e., manually assisted cough (abdominal thrust), air stacking with resuscitator bag or volume vent, or CoughAssist®. (*See below.*) If secretions are copious and caregivers or family are not available to use the CoughAssist®, suctioning and/or intubation may be required until patient improves enough to transition back to noninvasive ventilation.
- CoughAssist® is a portable device that many home mechanical ventilation patients, trached or otherwise, utilize to bring up secretions because they have a weak cough. This device must be by the patient's bedside and used as frequently as needed, possibly several times an hour until secretions are controlled. The patient and caregiver know how to operate this device and may prefer to operate it themselves.

5. **Caution!** Anesthesia and sedation for neuromuscular patients can dangerously decrease respiration.

Neuromuscular patients with respiratory muscle weakness develop respiratory failure due to hypoventilation. Anything that depresses their respiratory drive, such as opiates and benzodiazepines, will worsen hypoventilation and worsen respiratory failure. In noninvasively ventilated patients, sedating medications can blunt the patient's response to interface air leaks.

**Ventilation may eliminate the need for sedation.**

Medications such as narcotics and benzodiazepines are frequently used when patients appear to be dyspneic, anxious, uncomfortable or "fighting the ventilator." While these medications are important and should not be withheld if needed, healthcare providers need to be aware of the patient's respiratory status. For patients who typically use noninvasive ventilation, ***dyspnea and anxiety can frequently be relieved by starting noninvasive ventilatory support.***

## **If anesthesia is a must ...**

- It should only be administered by very experienced personnel under close monitoring.
- In the recovery room the patient should be returned to his/her home ventilation system (noninvasive or invasive) with his/her usual settings and with airway carefully monitored.

### 6. Using the patient's own ventilator is optimum.

The home ventilator is programmed to the settings used at home and the caregiver knows how to use it.

- *During short (less than one hour) ambulance transport*, use patient's home ventilator rather than bagging. For longer trips, connect the ventilator directly to the ambulance's AC power.
- *In hospital*, use patient's home ventilator. Otherwise, use hospital's equivalent device unless a more sophisticated form of ventilation is required. (If patient's equipment is pre-approved by hospital, patient will provide documentation.)
- Direct hospital RCP (Respiratory Care Practitioner) to consult by phone with patient's home RCP. See Patient's Vital Information for Medical Staff for contact information.

### 7. Not all body positions are tolerated by neuromuscular patients.

These patients often cannot tolerate positions normally assumed during treatment, such as lying on their backs. Ask the patient or caregiver about acceptable positions and ventilation needs during treatment.

### 8. *Important!* A tracheostomy is often unnecessary for patients previously using noninvasive ventilation.

As long as secretions can be managed noninvasively, there may be no need for tracheostomy support. Properly used noninvasive ventilation for a cooperative patient may provide as much respiratory support as invasive ventilation.

Generally, persons who are speaking and swallowing reasonably well do not need a tracheostomy for ventilation. They may require intubation temporarily for severe pneumonia or, like anyone else, for recovery from the trauma of surgery; **but they can usually transition back to noninvasive ventilation**. If possible, consult with the patient's physician. See Patient's Vital Information for Medical Staff before proceeding.

### 9. Life continuation/cessation is the patient's decision.

This patient has completed and discussed with his/her caregiver a Living Will and Medical Power of Attorney. The health professional's responsibility in this regard is specific and limited.

The health professional's responsibility **is to provide information** that will help the patient or the person designated as Power of Attorney to make a decision. For example: "Some tracheotomy patients can return to noninvasive ventilation over time."

The health professional's responsibility **is not to make judgments** about the patient's situation. *For example: "Your care in this condition will be too much for your family."*

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## Call for Proposals: IVUN's Fifth Research Grant

### Are you a researcher with an innovative idea for investigating neuromuscular disease?

Guidelines for applying are available:  
[www.ventusers.org/res/rfcall.html](http://www.ventusers.org/res/rfcall.html)

#### Dates to Remember:

- Monday, March 3, 2008  
Deadline for Phase 1 application
- Monday, April 14, 2008  
Invitation to submit Phase 2
- Monday, June 16, 2008  
Deadline for Phase 2 application  
(if invited by IVUN)
- Monday, November 10, 2008  
Announcement of recipient
- Thursday, January 15, 2009  
Receipt of \$15,000
- Wednesday, July 15, 2009  
Receipt of \$10,000

#### History of The Research Fund

Polio survivor and iron lung user Thomas Wallace Rogers bequeathed the initial funds for The Research Fund established in 1995. Grant awards are distributed from the interest gained on the corpus of the special segregated fund. Today, the fund's assets exceed \$620,000.

#### Past Recipients of The Research Grant

**2007:** *Pilot Study to Identify PPS Biomarker* by a team of researchers from the University of Arkansas for Medical Sciences (UAMS), Little Rock.

**2005:** *Timing of Noninvasive Ventilation for Patients with Amyotrophic Lateral Sclerosis* by a team of researchers from Johns Hopkins University, Baltimore, Maryland.

**2003:** *Women with Polio: Menopause, Late Effects, Life Satisfaction and Emotional Distress* by a team from the University of Michigan, Ann Arbor.

**2001:** *Ventilator Users' Perspectives on the Important Elements of Health-Related Quality of Life* by a team from the University of Toronto.

The final reports of the 2001, 2003 and 2005 grants are online at [www.ventusers.org/res/index.html](http://www.ventusers.org/res/index.html). The final report from the *Pilot Study to Identify PPS Biomarker* will be available in March of 2008.

Contributions to The Research Fund may be mailed to IVUN, 4207 Lindell Blvd., #110, Saint Louis, MO 63108-2930, or contributions may be made on our secure site at [www.ventusers.org/donForm.html](http://www.ventusers.org/donForm.html). If you have any questions, please call Joan L. Headley at 314-534-0475.

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