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.

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
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.
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).

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

<table>
<thead>
<tr>
<th>Document</th>
<th>Responsibility for Action</th>
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<tbody>
<tr>
<td><strong>Home Ventilator User’s Emergency Preparation Checklist</strong></td>
<td>Ventilator User completes it and, if desired, informs IVUN for recognition.</td>
</tr>
<tr>
<td><a href="http://www.ventusers.org/vume/HomeVentuserChecklist.pdf">www.ventusers.org/vume/HomeVentuserChecklist.pdf</a></td>
<td></td>
</tr>
<tr>
<td><strong>Caregiver’s Emergency Preparation Checklist</strong></td>
<td>Caregiver(s) completes it and, if desired, informs IVUN for recognition.</td>
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<tr>
<td><a href="http://www.ventusers.org/vume/CaregiverChecklist.pdf">www.ventusers.org/vume/CaregiverChecklist.pdf</a></td>
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</tbody>
</table>
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. 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 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.

Joan L. Headley, Executive Director
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Prepared by

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 ...
Ginny Brickley
Amy Kamp

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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 and info@ventusers.org

Funded by

Paralysis Resource Center
Christopher and Dana Reavis Foundation
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® 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® 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.

continued
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) and in its newsletter for this accomplishment.

Prepared by
International Ventilator Users Network
As an affiliate of Post-Polio Health International (PHI)

Funded by
Paralysis Resource Center
Christopher and Dana Reeve Foundation
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) and in its newsletter for this accomplishment.

Prepared by
International Ventilator Users Network
An affiliate of Post-Polio Health International (PHI)

Funded by
Peraffiasis Resource Center
Christopher and Dana Reeve Foundation
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.*
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.

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 O₂ 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 CO₂ levels. Oximetry and EtCO₂ (End Tidal) are preferable and adequate for measurement.
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.


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 _____________________________________________________________________
### MY CURRENT MEDICATIONS

<table>
<thead>
<tr>
<th>BRAND NAME</th>
<th>GENERIC NAME</th>
<th>Dosage &amp; Frequency</th>
<th>PURPOSE</th>
<th>When Begun</th>
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**This document belongs to**

**Name**

**Address**

City ___________________ State _______ Country ___________________

**Email**

**Phone** ___________________ Fax ___________________

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

Ventilator User Signature ___________________ Date ______________

Witness Signature ___________________ Date ______________
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Prepared by
International Ventilator Users Network
An affiliate of Post-Polio Health International (PHI)

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Paralysis Resource Center
Christopher and Dana Reeve Foundation
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. O₂ 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 CO₂ levels. Oximetry and EtCO₂ (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 on 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 for contact information.

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 tracheostomy 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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International Ventilator Users Network  
An affiliate of Post-Polio Health International (PHI)  
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Support International Ventilator Users Network’s educational, research, advocacy and networking mission.

Rates Effective 2007

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4207 Lindell Blvd, #110
Saint Louis, MO 63108-2930 USA
314-534-0475  314-534-5070 fax

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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

**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. 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. If you have any questions, please call Joan L. Headley at 314-534-0475.
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