



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.

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

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