Earlier this year, IVUN launched a project to gather information about flying with a vent: from users of home mechanical ventilation, from manufacturers and from airlines.

For traveling vent users, we posted a survey on our website at www.ventusers.org/adv/issues.html. It is available in English, Dutch, French and Spanish, and we will be accepting input until June 1. Users of HMV, both 24/7 and nighttime only, are encouraged to complete it. We have recorded data from 35 users (22 English, 6 Dutch, 3 Spanish, 4 French).

The second group we surveyed was the manufacturers of portable ventilators. To date, IVUN received responses from CareFusion, Covidien, GE/Breas, Impact Instrumentation, Newport Medical Instruments, Philips Respironics, Siare Engineering International Group, ResMed and Weinmann. Manufacturers of portable devices who are not listed should contact IVUN at info@ventusers.org so that their companies’ information is included in the final report.

We also contacted numerous airlines regarding their policies on using a ventilator during flight. To date, cooperation in providing information has been minimal at best.

Is there a solution?

Maryze Schoneveld van der Linde, a ventilator user from the Netherlands, is assisting IVUN with this international advocacy effort. She is actively advocating with the European Parliament to improve the rights of air passengers with disabilities.

At the recent international conference on HMV in Barcelona, Bernard Gaudon spoke about his experiences in traveling with a ventilator. He will post his entertaining presentation on http://bgaudon.tetraconcept.com, a site on which he tells his story as a polio survivor and ventilator user.

Also in Barcelona, Dr. João Carlos Winck, São João Hospital, Portugal, gave an informative talk entitled “Air travel and respiratory failure.” He asked if it is safe for patients with respiratory disorders to fly, discussing concerns for people with COPD, spinal cord injury, obesity hypoventilation syndrome and neuromuscular conditions. He discussed the reasons for oxygen use and ventilator support during flight.

Dr. Winck also referenced the timely and instructive “Managing passengers with stable respiratory disease planning air travel: British Thoracic Society recommendations,” developed by the Society’s Air Travel Working Group. The revised version was published September 2011 (Volume 66 Supplement 1 of Thorax.) The guidelines may be downloaded at www.brit-thoracic.org.uk/guidelines/air-travel-guideline.aspx.

Final report

IVUN will continue to gather information, and we encourage all members to visit the website and complete the survey by June 1. We will prepare a final report and fact sheets that will be posted on its website – www.ventusers.org in the fall of 2012.

Recognizing the fact that flying isn’t the only way to travel, IVUN will create an online searchable database for all ventilator users to report any kind of travel problem or success. We will notify IVUN Members when it is available for input and searching.