

### Traveling With Oxygen: Thoughts on the First International Meeting of Patients With Alpha 1-Antitrypsin Deficiency

**To the editor:** We read with interest the article by Díaz Lobato et al<sup>1</sup> about the RESPIRA expedition and the cruise with chronic obstructive pulmonary disease (COPD) patients. We were pleased to find that it is possible for such patients to travel and enjoy a holiday in spite of needing continuous oxygen therapy. Unfortunately our experience in a similar situation was not so satisfactory.

The congress AIR 2003: Third International Meeting on Alpha 1-Antitrypsin Deficiency took place in June in Barcelona. The AIR meetings have their origins in the desire of members of the Alpha 1-Antitrypsin International Register (AIR) to provide regular, updated, scientific and clinical information on this rare disease. The 2 previous meetings took place in Como and Rapallo, Italy.<sup>2</sup> At this third congress, and for the first time, a parallel international meeting was held for patients with alpha 1-antitrypsin deficiency and members of patients' associations, such as the Spanish Association of Patients with Alpha 1-Antitrypsin Deficiency. The patients' meeting was under the auspices of the Miami Alpha 1 Foundation in the USA and succeeded in bringing together 79 patients from countries in Europe, America, and Oceania. However, it is important to point out that attendance of this scientific conference by patients, especially by those who were seriously ill, gave rise to certain needs, which we are unaccustomed to managing and which require a fast, effective response. Here are some examples of the questions that were raised: Is a trans-oceanic journey with oxygen feasible? Can liquid oxygen be provided in airports between connecting flights, on transfers to hotels, or in conference halls? Have oxygen suppliers made logistical arrangements for international journeys, taking into account different health systems and airport security regulations? Who is responsible during the journey: the patient's usual doctor, the patient, the organizing doctor, the patients' association that extended the invitation? Who should take responsibility for organizing the patients' journeys: themselves, their doctors, the patients' association, or the

organizing committee? All of these questions make us wonder whether we are ready to cope with our patients' right to "lead a normal life." Perhaps scientific societies should take an active part in facilitating the disappearance of the barriers our "disabled" patients face. While the COPD cruise experience encourages us to promote this kind of project, it also creates new challenges that go beyond what has so far been considered "day-to-day clinical practice."<sup>1</sup> Situations of this kind will probably become more frequent in the future because of the increasing prevalence of COPD, the higher standard of living of the general population, and the greater number of air journeys being made. As early as 1995, British Airways, US Airways, and Qantas received a total of approximately 8 000 requests for in-flight oxygen.<sup>3</sup>

Most airline companies can supply oxygen to passengers during flights but have to be given prior notice, as it is usually necessary to submit medical information and fill in very detailed forms. The cost of this additional service varies from company to company, probably due to the lack of pertinent regulations.<sup>4</sup> However airline companies do not provide oxygen during stopovers and for this reason direct flights are always preferred. Passengers are not allowed to bring their own oxygen dispensers for security reasons, unless the cylinders or backpacks are completely empty.

We are familiar with the stories of 6 patients receiving oxygen therapy who expressed their intention to attend the AIR 2003 meeting. One lived in Barcelona, and three canceled their journey at the last minute, the first because of a partner's health problems, the second because of disease exacerbation in the previous month, and the third because the Spanish airline refused to allow the journey. Strangely enough, in the last case, the journey from Canada to Madrid with a Canadian company posed no problems; however insurmountable obstacles arose over the change to a connecting flight in Madrid, where permission to board with oxygen and without a doctor (to be provided by the patient) was denied and no alternative was offered by the airport authorities. The other 2 patients with oxygen equipment arrived without setbacks. It is worth pointing out that both arrived from other European countries on direct flights to Barcelona and flew with non-Spanish airline companies. This experience makes us wonder whether Spanish airport and airline personnel have the necessary awareness and training to respond to the needs of respiratory insufficiency

patients, who will be increasing in number and will have more and more need to travel.

Once on the ground the patients who had managed to reach their destination were able to enjoy the conference without major incidents in the supply of oxygen, and had no serious medical problems, although the organizers had provided for this eventuality by arranging for a pulmonologist to be on call at the hotel where the patients were staying.

The arrangements made by the hotel management and the company organizing the congress (BMC Medic) were both thorough and efficient. The main problems detected were the result of inexperience in journeys on the part of doctors, oxygen suppliers, and even patients, and also of the lack of regulations and useful guidelines in this area. Solutions to these problems should be found. Perhaps scientific organizations could cooperate in drawing up regulations or guidelines, on the model of the British Thoracic Society's recommendations,<sup>5</sup> for distribution among airline and airport management staff. Such guidelines would alert staff to the existence of this problem and ensure that everyone's right to travel is respected, even that of patients receiving continuous oxygen therapy. This means the right to travel without suffering setbacks or being subjected to exceptional demands, which are always directed at the weakest party, the patient.

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