

## The Fight for Home Care Ventilation in Brazil

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Until 2001, ventilation equipment in Brazil was provided only to those patients with chronic disorders who had the means to afford the home care structure, which is attached generally to private healthcare providers. Some of these patients remained hospitalized for a long time, often in ICUs.

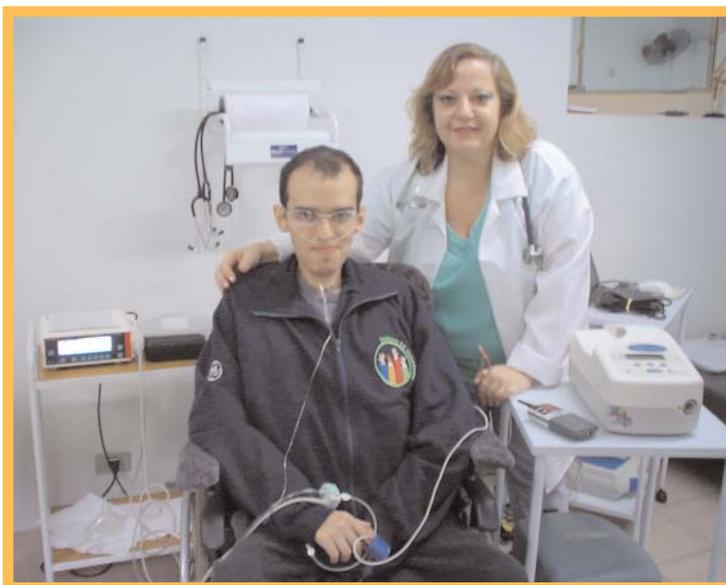
For the majority of patients – mainly those with neuromuscular diseases – the ventilation option was not even offered. The reasons include unawareness of the symptoms of respiratory failure and the consideration by the doctors' teams that the treatment was not worthwhile according to the patients' conditions.

Also in 2001, the *Grupo de Pais* (Parents of Children with Muscular Dystrophy Group) was founded and started to fight to save that generation of children. Members of the group, including myself, got in touch with the government, traveling three

times to Brasília, the capital, visiting members of parliament and cabinets in charge of helping people with disabilities. The group finally had a hearing with José Serra, the Health Minister.

On September 4, 2001, our great victory came: the *Portaria 1531* (a directive law) that gives all muscular dystrophy patients the right to have respiratory assistance through bilevel noninvasive ventilation as soon as the clinical situation determines the necessity. Our patients have about half a dozen masks from which to choose, and these are replaced every six months. (Volume ventilators are not included in the *Portaria*.)

Unfortunately, the law was only on paper, and it was not being respected. We started to advise patients to petition to obtain bilevel ventilation. As directors of ABDIM (Brazilian Muscular Dystrophy Association), we were called by the Public Prosecutor's



Diego is not using oxygen but is undergoing capnography testing.

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Office to give an explanation about why there were so many petitions. Touched by the situation, the prosecutor became an important ally and begged petitions against secretaries of state all over the country in order for them to also follow the *Portaria*.

The Health Secretariat of the State of São Paulo, where I live and which is the most developed and richest state in Brazil, called us and suggested we develop a state program for the distribution of bilevel ventilators. In that way, the structure of distribution of bilevel units was born.

The *Instituto do Sono* (Sleepiness Institution, [www.sono.org.br](http://www.sono.org.br)) was and still is in charge of the program in the State of São Paulo, but only 80 out of 108 patients from ABDIM have ventilation under its responsibility.

It is extremely important that the support groups, friends, family members and patients themselves organize and act side by side with health professionals to insist that regional teams follow the guidelines of the respiratory and ventilation programs.

Besides São Paulo, only Minas Gerais, another Brazilian state, has a ventilator assistance program. Unfortunately, in other states there is the necessity of judicial measures to get the device and, even when it is granted, we bump into the ignorance of health professionals about specialized equipment, such as the CoughAssist®, needed to live at home with ventilation.

After *Portaria* was promulgated, we returned three more times to Brasília to talk to three different health

ministers, asking them to broaden the *Portaria* to cover all the neuro-muscular diseases and to include the CoughAssist® in ventilation centers throughout the country.

***“It is extremely important that the support groups, friends, family members and patients themselves organize ...”***

**- Ana Lucia Langer, MD**

Unfortunately, our requests have not been completely granted, but we are obstinate, and we will go there as many times as necessary.

In the State of São Paulo, the *Instituto do Sono* has already acquired some CoughAssist® devices, and the Health Secretariat has bought some units for ABDIM.

ABDIM lends patients the use of the CoughAssist® when they face respiratory infections and need help in expelling lung irritants. The mortality level of our patients has fallen to zero, during the last two years, after acquiring these devices. ▲

### **ABDIM**

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