

Living with a Ventilator in Brazil

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Maria and Marcelo

I graduated in 1987 from Pontifícia Universidade Católica do Rio de Janeiro and began working as an electronic engineer at Centrais Eletricas Brasileiras – Eletrobrás (Brazilian Power System).

In 2000, I retired because my vital capacity had decreased greatly, due to respiratory complications while recovering from an emergency surgery to heal a bad abdominal infection and severe diverticulitis.

My retirement income is mainly what I live on because the government provides a very small financial aid to people with disabilities. I can say that I am really a lucky man, because I'm married to Maria de Fátima Lopes, a wonderful woman.

I received my first diagnosis of muscular dystrophy – Duchenne muscular dystrophy (DMD) – when I was about eight years old (1971). My parents began to notice some differences between my sister, who was a year older, and me. She ran faster, got up from the floor quicker, climbed stairs faster, jumped higher, and had more energy.

The DMD diagnosis was corrected some years later, because my progression was slower and didn't match that of Duchenne's. In fact I still don't have a definitive diagnosis, because my DNA test was inconclusive for DMD and a more detailed DNA test was too expensive for me. I probably have Becker's muscular dystrophy, although limb-girdle muscular dystrophy is another possibility, but with a lower probability.

I started using assisted ventilation in 1995, when I went into respiratory failure because of pneumonia and was trached. After recovering and letting the tracheostomy close, I began using a rented Respironics BiPAP® S/T during sleep.

The ventilator I use now is a Respironics BiPAP® AVAPS™, with an Advantage Series Silicone Nasal Mask that I like very much due to its durability and softness. This bilevel is quite small compared with the older BiPAP models, mainly because its power source is external, which keeps the BiPAP cooler.

My new BiPAP was supplied by the Brazilian Ministry of Health, after I won an eight-month lawsuit to force the Ministry to obey its own law about supplying a ventilator to all with muscular dystrophy who need assisted ventilation at home.

In Rio, the second richest state, an individual who goes to the Ministry of Health requesting a ventilator

with all the necessary documentation (including respiratory function tests and a doctor's order) is often told, "Unfortunately, there's no money to buy what you need." The only alternative is to sue the Ministry of Health, and sometimes (not often) cajole them into furnishing the equipment.

I know a situation where, after months of fighting, a boy received a nebulizer instead of a bilevel! One young woman with limb-girdle muscular dystrophy (www.acadim.com.br) has been waiting two years in a public hospital for the Ministry of Health to furnish the home care that a judge decided she should receive.

My physician, Ana Lucia Langer, MD, is Brazil's Muscular Dystrophy Association clinical director. She has fought hard for people like me to receive ventilators to be able to live at home. ▲