

My Experience with Setting Up Day-time Ventilation

Luke Melchior, Victoria, British Columbia, Canada, decaf@shaw.ca



Luke is 36 years old and uses a ventilator due to DMD. He and his wife live in a condominium in Victoria, BC. He receives 16 hours of attendant care per day from the British Columbia provincial health authority.

In the summer of 2005, I received a Legendair™ ventilator from the Provincial Respiratory Outreach Program (PROP), a government-funded program in Vancouver, British Columbia. This amazingly portable machine not only boasts an 11-hour internal battery (long enough so that I don't have to wire it into my wheelchair battery), but it also weighs less than 10 pounds and fits into a convenient backpack that attaches to my wheelchair.

The Legendair came at a time when I had been using my night-time ventilator (ResMed's VPAP® III ST) for an additional four hours during the day while I was in my wheelchair. The VPAP needed to be plugged into a wall outlet in order for it to operate, and this greatly impeded my mobility. Another drawback of using my night-time ventilator during the day was having to wear a nasal interface. The interface irritated my skin and also made it awkward for me to talk on the phone, see my computer screen and eat without aspirating.

Needless to say, when my Legendair arrived, I was determined to find a better interface to use with it. Luckily for me, my respiratory technician heeded my wish and set me up with an angled mouthpiece for mouthpiece ventilation. While this system managed to solve the issues I described earlier, the bracket used to hold the mouthpiece in front of my mouth created its own set of challenges. The bracket, which clamped onto the side

of my wheelchair, was bulky and difficult to adjust. Because it was affixed to my wheelchair, I would only be able to use the Legendair when I was sitting in the wheelchair.

Despite its limitations, that particular bracket was the only mouthpiece interface the technician could offer me at the time. I was not happy with this state of affairs so I decided to invent a new bracket. With the help of a different technician, I created a chestplate fitted with Snap-Loc bendable tubing to hold my ventilator hose and mouthpiece in place. Now the mouthpiece and hose were attached to me instead of to my wheelchair, and the hose could be easily readjusted with little to no effort.

The incredible battery life and light weight of the Legendair combined with a chestplate interface and mouthpiece allowed me to achieve complete portability for my daytime ventilation. Now I can breathe with ease whenever I have to travel by airplane or in a manual wheelchair. ▲

More about PROP

The PROP (Provincial Outreach Respiratory Program) began in 1998 in response to a crisis when the Ventilator Outreach program at Vancouver's Pearson Hospital closed. Coalescing around the idea of a provincial respiratory community outreach program, the Technology for Independent Living (TIL) program – housed on the same premises – and necessary clinical and administrative staff came together as a team consisting of client services, respiratory therapists, biomedical engineering technicians, peer supporters, and the ongoing clinical expertise of a respiratory specialist. Around the clock "on-call" services provide a centralized service to clients throughout British Columbia, giving individualized information and advice.