

## Data downloads for effective non-invasive ventilation in neuromuscular respiratory failure

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Conflict of Interest

C. LeBlanc has participated on the Respiratory Therapy Advisory Board for Philips Home Healthcare Solutions.

D. McKim has no financial or potential other conflicts of interest to disclose.

J. Sandoz has no financial or potential other conflicts of interest to disclose.

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## Introduction

Patients with progressive neuromuscular diseases (NMD), chest wall abnormalities, and diaphragmatic dysfunction are at high risk for the development of respiratory failure with resulting morbidity and mortality<sup>1</sup>. A large number of observational studies and a small number of randomized trials<sup>2,3</sup> have confirmed the effectiveness of noninvasive ventilation (NIV) in these individuals. Improvement in survival<sup>2,4-9</sup>, daytime symptoms of hypoventilation, quality of life, and arterial blood gases have all been documented<sup>10,11</sup>. However, few details regarding how to initiate and more importantly, how to follow these patients are reported. Recommendations regarding optimal adjustment of parameters such as ventilation modes (Spontaneous, Timed, Spontaneous/Timed, Pressure Control), back-up respiratory rates, inspiratory times, and rise times, are rare in the literature.

At a minimum, regular (twice yearly) clinical follow up of NIV settings with measurement of daytime gas exchange to assess adequacy of ventilation should be performed<sup>12</sup>. If there are any concerns, overnight oximetry can be considered, as well as follow up polysomnography with transcutaneous PCO<sub>2</sub> monitoring. While early morning arterial blood gases may be helpful, they are logistically difficult to obtain and may not reflect an abnormal time course of PCO<sub>2</sub> during the night<sup>13</sup>. Janssens et al. (2011) and McKim et al (2011) offer a further discussion on the monitoring of home NIV and some of the above mentioned variables<sup>13,14</sup>. As many of these patients have decreased mobility and difficulty accessing medical centres, we present other variables that can be followed in a real-life setting respecting patients' limited mobility and healthcare constraints.

Digital data, downloaded from home bilevel devices, provide information that can be used to estimate a number of variables and to infer the extent of respiratory muscle rest. Current bilevel ventilators allow for the extraction of compliance data directly to a computer. Neuromuscular respiratory care teams are increasingly using these capabilities, albeit with little guidance from the literature.

We discuss a case that illustrates the importance of combining appropriate follow up and clinical care with the adjustment of these variables using home bilevel download summary (DLS) information to increase patient comfort and adherence, decrease work of breathing, improve gas exchange, and ultimately, prolong tracheostomy-free survival.

### **Case Summary**

A 23 year old male with Duchenne Muscular Dystrophy (DMD) was referred to our outpatient clinic after having been advised to undergo a tracheostomy at another centre. He was wheel chair assisted and attended college full-time despite severe weakness and pulmonary restriction. He was symptomatic with dyspnea, frequent nocturnal awakenings, morning headaches, production of viscous white sputum throughout the night, ineffective cough and weight loss. Bilevel ventilation had been provided using the Synchrony (Philips Home Healthcare Solutions, Monroeville, Pa USA) for 11 months and parameters had been established in a sleep laboratory. Of note, all bilevel machines with back up rates in our health care system are publicly funded and there is no proprietary interest in any one type over the other.































