

VENTILATOR-ASSISTED LIVING

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“We can now go outdoors all day ... we enjoy every moment”

Submitted by Candy Wasserman, Senior Manager,
Global Product Marketing Communications, ResMed Ltd

Celine is almost 13 years old. Like most girls her age, technology means a lot to her, but it's not the latest phones or iPads that are of interest. For Celine it's a state-of-the-art portable ventilator that is most important.

Celine has needed a ventilator since birth. She was born with tracheomalacia (the cartilage in the trachea has not developed properly and instead of being rigid, the walls of the trachea are floppy). Because of this, along with a range of heart and lung problems, doctors predicted she was unlikely to live beyond 12 months.

However, ventilation was established. Operations were performed. Infections were treated. And after nine months, Celine was discharged from hospital – fully ventilated – to the care of her mother, Ariane.

At that time caring for a fully ventilated child at home was a relatively new occurrence – even in innovative Germany where Celine and her mother live. But Ariane was determined to give her daughter every opportunity to enjoy life and develop to her full potential.

Challenges were many. In the beginning the dry air being blown into Celine's lungs

was irritating, causing her to cough and making her vulnerable to infections. The air needed to be humidified, but finding the balance between sufficient moisture and too much fluid took a long time.

Celine is now established on the HumiCare™ humidifier, which she uses overnight and if she is ill. “HumiCare is fantastic,” says Ariane. Not only has it reduced the coughing but also Celine has had far fewer respiratory infections since she started on an earlier version of this device three years ago.

Another major challenge in Celine's case has been accessing the multiple services, therapies and even enjoyable activities that Ariane knew her daughter needed if she were to have a healthy and happy life.

Fundamental to meeting this challenge was to have a ventilator that was readily portable.

“It needed to be small and lightweight,” said Ariane, “and the batteries needed to last as long as possible.”

Ariane was packing three batteries along with everything else for a day's outing, when she was asked if she would trial Celine on ResMed's latest ventilator, Astral™, which has a battery life of up to 24 hours.*

The changeover of ventilators was done at home, without any problems, and immediately both Ariane and Celine noticed an advantage.

**Internal battery plus two external batteries*



Celine on an outing with her Astral.

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DMD Pathfinders Publishes Life and Breath: Worry Free Breathing During a Power Failure

DMD Pathfinders has produced a seven-page guide/fact sheet for people with Duchenne muscular dystrophy and others who use respiratory equipment (e.g., positive pressure machines/ventilators, cough assistance, nebulizers) to develop strategies and plans for emergency situations such as power failures. Compiled from the experiences of people who have faced such emergencies, it is a practical guide with checklists for developing an individualized plan of action. Click here to access: [Life and Breath pdf](#).



Screening device launched in St. Louis market

ApneaStrip™, the first disposable, in-home sleep apnea screening device for adults, launched in select St. Louis Walgreens® pharmacies on August 8, 2014.

People with untreated sleep apnea stop breathing for brief periods of time during their sleep, resulting in poor quality and insufficient sleep. According to the American Sleep Apnea Association (ASAA), sleep-disordered breathing affects as many as 43 million adults in the United States, most commonly in the form of sleep apnea. The ASAA estimates that at least 85% of sleep apnea sufferers go undiagnosed.

Untreated sleep apnea has been linked to a number of serious health concerns, including hypertension, diabetes and stroke.

ApneaStrip™ was created to address the growing need to easily and objectively identify potential sufferers of sleep apnea. It provides a simple, inexpensive first step for people who suspect they may have sleep apnea. A prescription is needed for the device for initial screening purposes. The retail pharmacy cost is \$29.99. Additional information can be found at www.apneastrip.com. ■

"We can now go outdoors all day ..."

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"The Astral is not as loud as the previous ventilator which used to sometimes wake us up at night," Ariane said. Its small size and weight make it easily transportable but it's the extended battery life that has made the biggest difference.

"We can now go outdoors all day," Ariane says. Celine attends physical therapy, speech therapy and even swimming. She can walk with a walker and is able to make sounds, which will hopefully soon become words.

Celine has not just survived full-time ventilation, she has flourished. "We enjoy every moment," Ariane says.

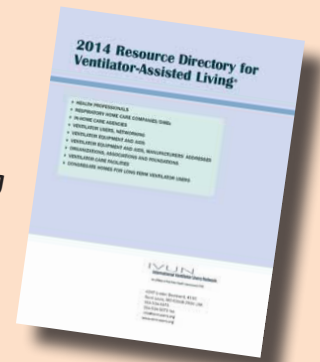
When considering the future, Ariane hopes her daughter "will have the freedom to do anything she wants."

It's a dream that would have been impossible when Celine was first ventilated over 12 years ago, but now given the new technology, it is a dream that looks well within reach. ■

IVUN Resources Updated

Resource Directory for Ventilator-Assisted Living

has been updated once again. IVUN's 47-page *Directory* is organized by country and state and can be downloaded for free from IVUN's website at <http://www.ventusers.org/net/vdirhm.html>. Should you or your facility be listed? If so, contact us at info@ventusers.org.



IVUN's Home Ventilator Guide is also up-to-date. The grid-like design includes the details of the many devices available for use in the home, e.g., bilevel positive airway pressure devices, volume-cycled ventilators, pressure support ventilators and combination or multi-mode ventilators. The 27-page *Guide* can be downloaded for free at www.ventusers.org/edu/HomeVentGuide.pdf