

AbilityPath.org releases comprehensive guide

Will help families with special needs children prepare for challenging transition period

Millions of American families of children with special needs, ages 5 to 17, will be going back to school this month and taking one step closer to facing the critical transitional period from high school to adulthood. To assist those individuals and families with this stage in life, and to reduce the stress and impact on the household, AbilityPath.org released a comprehensive new report and guide, "The Journey to Life After High School: A Road Map for Parents of Children with Special Needs." This report examines the laws that impact youth with special needs, the importance of the individualized education plan and the different paths a young adult with special needs can take after graduating from high school. A national state-by-state directory of supporting agencies is included.

The report and resource guide was released on August 12, 2014, and is available for FREE download at www.abilitypath.org/lifeafterhighschool.

FDA expands approval of drug to treat Pompe disease

The U.S. Food and Drug Administration recently announced the approval of Lumizyme (alglucosidase alfa) for treatment of patients with infantile-onset Pompe disease, including patients who are less than 8 years of age. In addition, the Risk Evaluation and Mitigation Strategy (REMS) known as the Lumizyme ACE (Alglucosidase Alfa Control and Education) Program is being eliminated.

Pompe disease is a rare genetic disorder and occurs in an estimated 1 in every 40,000 to 300,000 births. Its primary symptom is heart and skeletal muscle weakness, progressing to respiratory weakness and death from respiratory failure.

The disease causes gene mutations to prevent the body from making enough of the functional form of an enzyme called acid alpha-glucosidase (GAA). This enzyme is necessary for proper muscle functioning. GAA is used by the heart and muscle cells to convert a form of sugar called glycogen into energy. Without the enzyme action, glycogen builds up in the cells and, ultimately, weakens the heart and muscles.

Lumizyme is believed to work by replacing the deficient GAA, thereby reducing the accumulated glycogen in heart and skeletal muscle cells.

Myozyme and Lumizyme are marketed by Cambridge, Massachusetts-based Genzyme.

New DMD drug conditionally approved

Ataluren, a drug being developed by PTC Therapeutics to treat Duchenne muscular dystrophy caused by specific genetic mutations, has received conditional approval in the European Union; Muscular Dystrophy Association gave a \$1.5 million grant to PTC in 2005 for ataluren's development.

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International Ventilator Users Network's mission is to enhance the lives and independence of home mechanical ventilator users and polio survivors through education, advocacy, research and networking.

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Moving? Change of address?

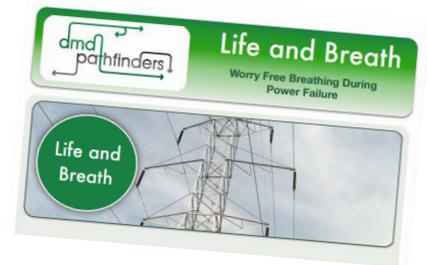
Notify IVUN before you move by calling 314-534-0475 or email info@ventusers.org, and tell us your old and new addresses.

Away temporarily?

Send us your second address and dates you will be there and we'll do our best to send you your newsletter.

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.

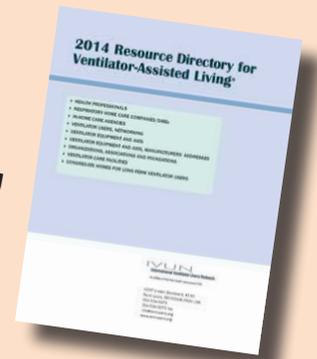
When considering the future, Ariane hopes her daughter "will have the freedom to do anything she wants."

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