

Matt Eddy's Journey of a Million Smiles

It may be a while before Matt Eddy knows if Guinness World Records certifies his "Journey of a Million Smiles" from coast to coast. But he knows for sure that between June 5 and October 9, 2010, he successfully traveled some 3,400 miles from Lynn, Massachusetts, to Long Beach, California, in his power wheelchair while using a ventilator to breathe.



Matt Eddy is greeted with a congratulatory banner in Long Beach, California, after his 3,400-mile cross-country trip in a wheelchair. Pictured on the banner with Matt is his travel crew – Dani Shirtcliffe, Ron Steenbruggen and David Lau, the driver.

Photo credit: Janus Angus Baker, Newport Medical Instruments, Inc.

Diagnosed at age 4 with Duchenne muscular dystrophy, a severe recessive neuromuscular disease characterized by progressive muscle degeneration, Matt has used a wheelchair since he was 10. He has used a ventilator since having a tracheotomy at age 20. Now 33 years old, he operates his wheelchair with the only two fingers he can still move.

Accompanied by his respiratory therapist,

Ron Steenbruggen, Ron's daughter Dani and a friend, plus two Boston terriers, Matt set a goal of raising \$1 each from a million people for Matt's Place Inc., (www.officialmattsplace.org) during his trek across America. Contributors could sign the RV that housed Matt and crew at night. To gain more visibility for the effort, Matt received approval from Guinness World Records to register a new category: Trans-USA by Wheelchair.

Matt's Place was created 10 years ago when Matt was dismissed from a rehabilitation facility and needed customized, accessible housing. Ron was an RT at the facility and, recognizing Matt's dilemma, bought and renovated a house adapted to Matt's needs. Since then, Matt's Place has incorporated as a nonprofit organization whose mission is to build accessible housing, provide community awareness and education, offer personal care staff assistance and help with the transition from health care facilities to home.

"The cost of institutionalization is extraordinary," said Ron. "The fact is that people are happier and stay healthier in their own homes, but they face financial and daily living challenges in finding appropriate housing. Instead of focusing on research and cures, the mission of Matt's Place is to improve the lives of individuals with severe disabilities."

Matt and Ron had made the trip two years earlier by wheelchair and bicycle, to raise awareness for people with disabilities who want to live independently and to fulfill Matt's dream of seeing the country. They camped in a tent at night, but found that it took

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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.

Ventilator-Assisted Living
December 2010, Vol. 24, No. 6

ISSN 1066-534X

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Special thanks ...

Judith R. Fischer, MSLS

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From Around the Network

Judith R. Fischer, IVUN Information Specialist, info@ventusers.org

New Products

ATHENA, a new multi-mode ventilator (for invasive and noninvasive ventilation) from Dima Italia, S.r.l., can be used with both a single- or double-limb circuit. The touch screen color monitor is easy to read and use. Lightweight (3.5 kg, 7.7 lbs.) and compact, the ATHENA's rechargeable internal LiPo battery lasts up to 12 hours. ATHENA is not available in the USA. www.dimaitalia.com



OPAP® Dental Appliance from OPAP Health Care offers an alternative to vent users who cannot adapt to or tolerate nasal and facial masks. The custom-made appliance is simply inserted into the mouth and held in place by the upper and lower teeth. The company works in conjunction with the individual's dentist to get impressions of the mouth and teeth. For more details, visit www.opaphealthcare.com.



Travel

"Flying with Ventilation" is the name of a working group spearheaded by Maryze Schoneveld van der Linde, a vent user in the Netherlands. Concerned about the increasing problems vent users experience when planning to travel by plane in Europe, Maryze (project manager at the European Neuromuscular Centre for the EU project TREAT-NMD) persuaded a member of the European Union parliament to present the group's concerns to the EU. These concerns (to list a few) include being refused to travel by the airlines, often on short notice; complicated procedures in finding out how to get approval to fly; and determining which airlines allow people to use their ventilator on board without hassles. For complete information, email Maryze, maryze@xs4all.nl, and visit www.ventusers.org/adv/LtrToEUflyingWvent.pdf.

Speech Aid

Voice Aerobics™ Songbirds is the latest in a series of CDs with speech and voice exercises set to music by Mary Spremulli, MA, CCC-SLP. Spremulli designed the exercises for individuals with changes in speech and voice due to neurological conditions. The Songbirds CD is available for \$15, plus shipping and handling. Visit www.voiceaerobicsdvd.com and <http://aerobicsdvd.blogspot.com>.

New Vent Users' Discussion Group

A new Internet discussion group for vent users is available through Google. Go to <http://groups.google.com/group/vent-users>. ▲

Ask The Experts

In the last issue of *Ventilator-Assisted Living*, Dr. John Bach's answer in the Ask the Experts column prompted this response from a reader: ***Dr. Bach stated that the BiPAP is "suboptimal" for resting lung muscles at night. As a BiPAP S/T user for 10 years due to PPS, please suggest the names of ventilator equipment which should be used for night rest of lung muscles.***

Dr. Bach responded: *For people who want to understand why BiPAP is suboptimal, that is, since you can not turn off the EPAP, and the IPAP is rarely set high enough to fully rest the inspiratory muscles, ventilators like the LTV series, Trilogy and Newport can be recommended. Any ventilator without EPAP is more appropriate.*

BiPAP would be OK at settings of IPAP 22 to 30 and EPAP minimum. But because of the EPAP, it is less comfortable this way, and it cannot be used for air stacking. This is discussed in my book, "Management of Patients with Neuromuscular Disease" available at www.doctorbach.com

Ventilator-Assisted Living asked the three recommended ventilator manufacturers to elaborate on what features of their product(s) address this issue.

Roxanne Venard, RRT, Manager, Clinical Services, Alternate Care, CareFusion,
roxanne.venard@CareFusion.com

The LTV series ventilators can provide rest of the respiratory muscles, but the selection of a breathing mode, such as assist/control (A/C) or synchronized intermittent mandatory ventilation (SIMV), depends on the amount of support the patient requires to rest those muscles.

In the A/C mode, a breath rate and tidal volume or pressure are set to meet the patient's ventilatory requirements. (Tidal volume is the amount of air and/or oxygen that is delivered with each breath. A pressure breath is a specified amount of pressure that is delivered with each breath.) The ventilator guarantees a minimum number of machine-delivered volume- or pressure-controlled breaths. The patient may trigger additional assisted breaths of the same set volume or pressure.

If the SIMV mode is selected, the breath rate, a tidal volume or pressure, and pressure support are set. Pressure-support breaths are patient-triggered breaths for which the tidal volume is not set, and the breath ends by either a decrease in set percent of the breath peak flow or a specified time, whichever comes first. In SIMV mode, machine, assist and patient breaths may be given. For the first patient-triggered breath detected within a breath period, an assist breath is given. For all subsequent patient-triggered breaths within the same breath period, pressure support breaths are given. At the beginning of a breath period, if no triggered breaths were given in the previous breath period, a machine breath is given.

Cyndy Miller, RRT, Clinical Education Manager, Newport Medical Instruments, Inc.,
CMiller@nmitkb.com

The Newport HT70 and HT50 ventilators offer the clinical capabilities needed to provide partial or full inspiratory muscle rest for people who need to use assisted ventilation due to neuromuscular disorders including post-polio syndrome, ALS and muscular dystrophy.

At night, noninvasive HT70 users are ventilated through a mask using the A/C or SIMV modes, and either pressure-control or volume-control ventilation. The range of pressures and volumes available is high enough to ensure that the ventilator does the breathing work, and the

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Ask the Experts

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user's muscles are allowed to rest and recover.

During the day, many HT70 noninvasive users prefer the flexibility of mouthpiece ventilation via the sip technique in which the user sips on a mouthpiece to initiate a breath, and then takes one or more breaths before letting go of the mouthpiece. Typically, the A/C mode with volume-control ventilation is selected so users can breath stack in order to expand and maintain lung volumes, and chest wall compliance.

Elaine Lesnak, Senior Marketing Manager, Philips Respironics, Elaine.Lesnak@philips.com

The Trilogy series of ventilators (Trilogy100, Trilogy200, Trilogy202) offers both pressure- and volume-controlled ventilation for either invasive or noninvasive use. The Trilogy, in an independent performance evaluation, was found to be the least

affected by leaks that can happen around trach tubes or nasal or face masks. The benefit to ventilator users is that the tidal volume that is selected is more consistently delivered during breaths, even in the presence of a leak. The evaluation also concluded that Trilogy consistently and accurately delivered the pressure that had been chosen, providing assurance that the user is being ventilated properly.

In the same evaluation, Trilogy required the lowest effort by the user to trigger a breath, thus offering a more sensitive delivery of breaths and possible decrease in the work of breathing. This improves the synchrony between the patient's breaths and those provided by the ventilator.

The Trilogy has a full range of modes, including A/C and SIMV, and with the appropriate choice, ventilator use is more comfortable. ▲



Barbara Rogers and Norma Braun, MD, at the CHEST 2010 Convocation in Vancouver, British Columbia, Canada, on October 31.

Barbara Rogers Awarded Pfrommer Memorial Lecture

Barbara Rogers, president of the National Emphysema/COPD Association, was awarded the 2010 Margaret Pfrommer Memorial Lecture in Long-Term Ventilation from the American College of Chest Physicians (ACCP).

The lecture, entitled "Behind Closed Doors: Confessions of a Ventilator User," featured Rogers' own case history as a vent user and partnerships with physicians regarding her health care. Preliminary data from her survey of ventilator users and video clips of ventilator users around the world were also presented.

Alan Goldberg, MD, and his wife Eveline Faure, MD, established the lecture in 1999 to encourage the "patient perspective" at ACCP meet-

ings to ensure that individuals who use mechanical ventilation can work more effectively as partners with their health care team.

"Margaret Pfrommer was a polio survivor and was assisted by mechanical ventilation for more than 45 years," said Goldberg. "She was our friend and teacher who made us listen and understand her situation."

The Margaret Pfrommer Memorial Fund is administered by the CHEST Foundation, the philanthropic arm of the ACCP whose mission is to provide resources to advance the prevention and treatment of diseases of the chest.

www.chestfoundation.org ▲

Matt Eddy's Journey of a Million Smiles

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several hours each day to set up the tent and Matt's equipment – suction machine, ventilator, humidifier and battery charger. For this trip, the RV would house the equipment and provide a more comfortable environment for sleeping.

But during the day, Matt and Ron still had to brave the elements ranging from below freezing temperatures in the mountains to 114 degrees on their hottest day in the desert. "Humidity, altitude and temperatures were challenging," Ron said. "We went through rain and hail, and below 30 degrees, the tubes would freeze."

Matt uses a Newport HT50 vent. "During the day, he deflated the cuffed trach, and if we went above 10,000 feet, he inflated it to give him extra volume," said Ron. Newport Medical, Inc. helped sponsor Matt's journey, and hosted Matt and his team at their Costa Mesa, California, headquarters after he crossed the finish line. Many Newport employees personally contributed and signed his RV.

Matt got a new wheelchair before they left, but its top speed was only 3 to 4 miles per hour, so he opted to use his old chair that could run up to 8 miles per hour. He wore out three sets of wheelchair tires over the course of the trip.

One of the biggest challenges they faced on the trip was satisfying all the Guinness World Record requirements. Every minute of travel had to be recorded on video, which required a heavy-duty camera that could be strapped to the back of the wheelchair. All those hours of video had to be downloaded every night.

"At first, we didn't realize that the camera would shut down if the temperature was more than 104 degrees,"



To raise funds for Matt's Place, Matt asked for \$1 from anyone who wanted to sign the RV. Judith Fischer, IVUN Information Specialist, conveyed IVUN's congratulations.

Photo credit: Janus Angus Baker, Newport Medical Instruments, Inc.

said Ron. "We had to do 8 miles over one day when we discovered it hadn't been recording. We had to keep a log of all the people we met and ask that they sign it, and we had to get official timekeepers to verify the beginning and end of the trip."

In addition to the incredible natural beauty they experienced – from Niagara Falls to the Grand Canyon – Ron says that they were struck by the kindness of people as they crossed America. While they fell short of their million-dollar goal, "We raised about \$70,000 for Matt's Place, so technically we're still on the "Journey," Ron said. "Matt came down with pneumonia after the trip, but when he's well enough, we will start our fundraising efforts again."

Meanwhile, Guinness staff is reviewing hundreds of hours of video before certifying the journey as a world record. ▲

Donations to Matt's Place are tax deductible and can be made payable to Matt's Place c/o Eastern Bank, 156 Boston St., Lynn, Massachusetts, 01904 or online at www.officialmattsplace.org/donations.htm

Breathing & Sleep Symposium II

Judith R. Fischer, IVUN Information Specialist, info@ventusers.org

Building on the successful 2009 program about the breathing and sleep problems of individuals with neuromuscular (NM) conditions, new topics at the November 21, 2010, symposium covered pulmonary function tests and pre- and post-operative surgical considerations. The audience of primarily polio survivors also included respiratory therapists and trainees from the local San Diego area who received continuing education credits for the five-hour program. The setting was again the Salk Institute for Biological Studies in La Jolla, California, and sponsors were the Salk Institute and ResMed Corp.

Presenters included Josh Benditt, MD, FCCP, and Louie Boitano, MS, RRT, RPFT, the Northwest Assisted Breathing Center at University of Washington in Seattle; Helen Kent, BS, RRT, Progressive Medical, Carlsbad, California; Selma Calmes, MD (retired), UCLA School of Medicine; and Angela King, BS, RPFT, RRT-NPS, ResMed Corp.

HIGHLIGHTS

Sleep-disordered breathing, tests and equipment

■ During sleep, everyone breathes less deeply but when there is also respiratory muscle weakness, individuals can get started on the slow road to respiratory insufficiency.

■ Sleep studies may not be necessary when pulmonary function tests such as MIP (maximum inspiratory pressure), MEP (maximum expiratory pressure), peak cough flow, and FVC (forced vital capacity) can identify breathing problems and underventilation due to weakening respiratory muscles. It is important to measure FVC in the supine (lying face up) position.

■ Most sleep labs are not set up for people with neuromuscular conditions who may have breathing problems due to underventilation. CPAP units are appropriate for obstructive sleep apnea, but when underventilation is present, the appropriate equipment is a bilevel device with a backup rate that can initiate breaths for the individual.

■ Oxygen may be necessary but should *only* be used in conjunction with assisted ventilation.

■ Pulse oximetry measures O₂ saturation, but not CO₂ buildup.

■ Follow-up monitoring after assisted ventilation has been initiated is important, but often not done. Annual tests of MIP, MEP, and FVC are recommended to monitor progression of respiratory muscle weakness.

Pre-op and post-op considerations

■ When possible, choose a large teaching hospital, and check out the surgeon carefully.

Gladys Swensrud (third from left), Co-facilitator of the San Diego Polio Survivors, with (from left) Louie Boitano, Selma Calmes and Josh Benditt, presenters at the Breathing and Sleep Symposium II.

Photo credit: Nancy Yates



Dear Editor:

I just finished reading the August 2010 issue of *Ventilator-Assisted Living*. It is very good, as usual. I want to add additional comment to the "Ask the Experts" article and the Passy-Muir article.

Speaking is critical to a respirator user. Unfortunately, some physicians just don't get it. In both of these articles this was indicated, but it goes beyond weaning from a trach or using a speaking valve.

My good friend, Ken, entered a very well respected health facility in 2003 for a routine gallbladder removal. Something went wrong and he never regained peristaltic action. He became so distended that his breathing was compromised. He needed a tracheostomy to get adequately ventilated. A cuffed trach was used.

Ken was in the hospital, mostly in ICU, for almost four months. In this time, his cuff was never deflated. As far as I could determine, his cuff was not deflated for even brief periods. This is contrary to all cuffed trach protocols. When I questioned his respiratory therapist about deflating his cuff, I was told very firmly, "He's not ready to come off the vent yet!"

I pointed out that I'm on a vent. I have a trach. And I don't use a cuff. The therapist looked at me as if I were an alien being. I left notes for Ken's physicians in his medical charts and spoke often with his nursing team. They appeared to be in agreement with me. Unfortunately, his primary doctor never returned my calls. I was not a relative, so I had little standing to press the issue. A relative who had his medical power of attorney believed that, "The doctor must know what he's doing."

Ken died of sepsis three and a half months after entering the hospital, never having the opportunity to speak.

Richard Daggett, President, Polio Survivors Association, Downey, California, richarddaggett@ca.rr.com

- ▷ ■ Complications are due more to the surgery than the anesthesia.
- Meeting with the anesthesiologist before surgery, while preferable, may not be possible. Many large hospitals have pre-op clinics that can take the information and pass it along in case the anesthesiologist should change.
- Post-op phase can be critical for people with NM disorders; these individuals need closer monitoring and should not be discharged too quickly.
- If the hospital permits, the individual can bring his/her own ventilator and interface to use, but this requires discussions with hospital staff as surgery is being planned.

Gladys Swensrud, Co-Facilitator of the San Diego Polio Survivors, was saluted for her hard work in organizing and promoting the symposium. Videos of the presentations are available on www.poliotoday.org. ▲

Calendar

MARCH 12-18. Ventilator-Assisted Children's Center (VACC) Camp, Miami Florida. Contact Bela Florentin, VACC, Miami Children's Hospital, 305-662-8222, bela.florentin@mch.com, www.vaccamp.com

MARCH 24-26. FOCUS on Respiratory Care and Sleep Medicine Annual Conference. The Town & Country Resort, San Diego, California. www.foocus.com

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Philips Respironics is expanding the company's solutions for patients who suffer from chronic respiratory diseases with the introduction of the Trilogy200 ventilator. The Trilogy200 meets the needs of patients that require enhanced triggering sensitivity and monitoring in the home and alternative care settings. For more information: <http://trilogy200.respironics.com>



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