VENTILATOR-ASSISTED LIVING

June 2013 Volume 27 Number 3

www.ventusers.org

Demystifying End Tidal CO₂

Bonnie Jo Grieve, MD, Dousman, Wisconsin, bjgrieve@gmail.com

I am a new post-polio ventilator user. I had polio at age 4 in 1953, was completely paralyzed and probably in an iron lung briefly. Now I have severe kyphoscoliosis (front-to-back and side-to-side curvature of the spine) and new weakness.

Two years ago I was started on an S9 CPAP (ResMed) but was unable to breathe out

against the pressure, so was switched to a Respironics AVAPS BiPAP (Philips Respironics) initially with low span settings. After a year of continued awakenings with tachycardia, I upped the settings to high span, IPAP currently at 20 and EPAP 5, and have been sleeping through the night

ever since.

"The situation gets complicated for those of us unable to respond adequately to our need for oxygen."

Every week brings new information about neuromuscular hypoventilation. In February 2013, IVUN hosted a phone conference featuring physiatrist Dr. John R. Bach and his recommendations regarding relying on noninvasive ventilation (NIV) for as long as possible for most neuromuscular ventilation needs. His books discuss NIV, pulse oxygen monitoring, CoughAssist with manual thrusts if necessary, and end tidal carbon dioxide (CO₂) monitoring for CO₂ retention. This raised questions about CO₂ monitoring.

Understanding CO₂

Carbon dioxide is a byproduct of the metabolism of oxygen and glucose for producing energy. CO₂ diffuses out of cells and into the blood in our lungs and diffusing into our alveoli before exha-

lation. It can be measured in two ways. One way is measured by drawing arterial blood gases (ABG). This measurement is represented as PCO₂ (the partial pressure of carbon dioxide, the relative concentration of the gas in our blood). The other is to measure CO₂ at the end of exhalation as we breathe air out, which is called End Tidal CO₂ (EtCO₂).

Measuring PCO₂ by ABG involves drawing blood from an artery, usually the radial artery at the wrist or sometimes the femoral artery in the groin, and lab analysis. Obtaining an EtCO₂ measurement is painless, usually with a tiny cannula (tube) placed under our masks, just inside our nose or mouth, whichever we use to exhale, or in the exhalation port of our ventilator set up. The EtCO₂ correlates with the PCO₂ from our arterial blood, but does not require any blood draw, just a small sample of the air we breathe out.

The Role of Breathing

Breathing accomplishes both bringing in oxygen and expelling CO₂ as a waste gas. The amount of breathing we do is usually determined by how much oxygen our chemoreceptors sense in our blood. If we breathe more, we take in more oxygen but exhale more CO₂, and our CO₂ goes down. If we breathe less, our CO₂ keeps being produced by our cells, but not enough is exhaled, so CO₂ rises. The situation gets complicated for those of us unable to respond adequately to our need for oxygen. Neuromuscular deficits may be too extensive to take in sufficient air to expand enough alveoli to absorb

continued on page 6



Ouattro™ Air

Send product news to info@ventusers.org

New Products

Quattro™ Air full face mask from ResMed weighs only 3.3 ounces. The dual-wall Spring Air™ cushion provides more comfort at the bridge of the nose, while the cutout at the chin provides a better seal. Other features include flex-wing forehead support; comfortable headgear; and one-piece elbow, swivel and anti-asphyxia valve. Available in three sizes each for men and for women. www.resmed.com

RespIn 11 HFCWO Bronchial Clearance System is a new high frequency chest-wall oscillation device from MedInnovation Technology Group, Inc. It uses a patented system of valves, electronic control and targeted pressure pistons to deliver pulsations directly to targeted areas of the chest to loosen secretions. It operates at a low background pressure for more comfortable treatment. www.medinnovationtechgrp.com

Pompe Disease Gene Therapy

Researchers at the University of Florida Health in Gainesville recently reported results from a clinical trial of gene therapy. The therapy improved respiratory function in individuals with Pompe disease, a rare inherited metabolic disease. It occurs in children who are born with mutations in a gene responsible for the production of an enzyme vital to converting glycogen in the body to glucose. The lack of the enzyme leads to an accumulation of glycogen in the muscle which leads to muscle weakness, affecting the ability to walk and breathe. After a six-month follow-up, the gene therapy was deemed safe and shown to increase the time the trial participants could spend breathing on their own without assisted ventilation. The results of the study were published in Human Gene Therapy. www.liebertpub.com/hum, www.worldpompe.org

Ventilator Industry Report

"Mechanical Ventilators: A Global Strategic Business Report," recently released by Global Industry Analysts, Inc., provides a comprehensive review of trends, issues, strategic industry activities and profiles of major companies worldwide. The mechanical ventilators' market is expected to reach \$3.9 billion (USD) by 2018. The cost of the report is \$4,950. For more information, go to www.strategyr.com/Mechanical_Ventilators_Market_Report.asp.

Update on Virus Outbreaks

Since the H7N9 avian virus outbreak in China at the end of March, the virus has infected 132 people and claimed 37 lives. Most of the H7N9 infections have involved poultry-to-human transmission, but the potential for an endemic spread due to transmission between humans exists. There is little to no human immunity to this new virus. A group of researchers at the University of Hong Kong has designed a diagnostic test with high specificity for the H7N9 virus that can be processed within three hours.

continued on page 7

VENTILATOR-ASSISTED LIVING

June 2013 Vol. 27, No. 3

ISSN 1066-534X

Editor: Gayla Hoffman, info@ventusers.org Designer: Sheryl R. Rudy, webmaster@ventusers.org

©2013 Post-Polio Health International (PHI). Permission to reprint must be obtained from Post-Polio Health International (PHI).

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.

How to contact IVUN

Executive Director Joan L. Headley, MS info@ventusers.org

4207 Lindell Blvd., #110 Saint Louis, MO 63108-2930 USA Phone: 314-534-0475 Fax: 314-534-5070 info@ventusers.org www.ventusers.org

Like us on Facebook.
International Ventilator Users Network (IVUN)

To be sure you receive email updates from PHI and IVUN, set your spam filters to allow messages

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.

from info@post-polio.org and info@ventusers.org.

Away temporarily?

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

How Polio Survivors Can Avoid Tracheostomies

Joan L. Headley, Executive Director, International Ventilator Users Network, St. Louis, Missouri

John R. Bach, MD, Physical Medicine & Rehabilitation, University Hospital, University of Medicine & Dentistry of New Jersey, Newark, New Jersey, is in charge of the Center for Noninvasive Mechanical Ventilation Alternatives and Pulmonary Rehabilitation and has spoken and written

extensively. His most recent contribution to the literature is "Management of Patients with Neuromuscular Disease" by Hanley & Belfus (2003).

"There are also some people who never before needed assisted ventilation until recently."

Prior to his presentation on February 27th, Dr. Bach submitted "Respiratory Muscle Aids to Avert Respiratory Failure and Tracheostomy," which can be found at www.ventusers.org/edu/ConfCall2013 Bach.pdf. His talk supported the premise that "Polio survivors can virtually ALWAYS avoid tracheostomies even if continuously (noninvasively) ventilator dependent," which he did by expanding on several statements.

Dr. Bach describes his patients: My first patients were those who used ventilators after having had polio. Then, I started seeing patients who had used iron lungs but had been weaned from them but now needed to use noninvasive ventilation. There are also some people who never before needed assisted ventilation until recently.

Dr. Bach on the decision to use assisted ventilation: First, it should be determined if polio survivors are symptomatic for nocturnal underventilation. It is also possible that there could be a second condition like lung disease (failure of oxygenation) especially if one was a heavy smoker. Most of the time, though, the symptoms are from muscle weakness (failure of ventilation) for which the treatment is nocturnal ventilation. This

is most likely for the survivors of polio. The treatments are very different. For lung issues, the solutions include bronchodilators and oxygen. But, for muscle weakness, the treatment is the use of respiratory aids which include noninvasive ventilation and mechanical coughing aids.

If a patient has both problems, e.g., lung problems due to smoking and neuromuscular weakness due to polio, a decision may need to be made as to which is the primary problem and treat it.

Dr. Bach on breathing muscles: Inspiratory muscles assist with inhaling. Shortness of breath when lying flat (orthopnea) is a sign of a weak diaphragm (an inspiratory muscle). Many polio survivors use pillows to support their backs to prevent shortness of breath when they sleep, but the best solution for weak inspiratory muscles is intermittent positive pressure ventilation (air under pressure when inhaling) from a ventilator and via a nose interface. It takes about 20 ml of water pressure to ventilate someone who has severe muscle weakness.

Expiratory muscles (mostly the abdominals) assist with coughing. If survivors get a cold, they may not complain of shortness of breath but of anxiety and difficulty sleeping due to high blood carbon dioxide levels.

It is not helpful to use CPAP and only minimally helpful to use bilevel devices if breathing muscles are weak, because the air blowing in when one exhales is counterproductive.

Bulbar (throat) muscles protect the airways. There isn't anything to be done for bulbar muscle weakness when it results in continuous aspiration of saliva into the lungs, but in polio that almost never

continued on page 4

continued from page 3

happens, which is why tracheostomy tubes are unnecessary.

Dr. Bach on weak coughing muscles:

Weak coughing muscles keep one from getting rid of the bacteria, etc. in the lungs, which results in pneumonia risk. The first thing an ER physician normally would do is to give oxygen, and if the CO₂ is already high it will "go through the

"It's a terrible mistake for polio survivors (without lung diseases) to use oxygen." roof." This is why and how many polio survivors get intubated and, after the pneumonia clears up, many are trached. It is not necessary. If a person

could speak and swallow at least a little before getting intubated he/she certainly does not need a tracheostomy. Do polio people have trouble swallowing? No. But, people with ALS have trouble swallowing, and they can need tracheostomy tubes.

Dr. Bach on CoughAssist (Philips

Respironics): Some people who have a trach think that it is easier to suction mucus when they have a cold if they have a trach. The only people who think this are those who don't know how to use the CoughAssist through the nose and mouth. For that matter, it is also much better than suctioning the airways to use it via a trach tube, too. It is best to use the CoughAssist with an abdominal thrust and at least 35 ml of water pressure in and out. A manually assisted cough will get most polio survivors a functional cough to help them through most problems, so a cough machine is not as necessary for everybody.

Dimi Italia s.r.l., Seoil Pacific Group, B & D Electromedical and Siare Engineering International Group S.r.l. also manufacture cough devices, but not all are available in the United States. (Go to www.ventusers.org/net/VentDIR.pdf for further information on manufacturers.)

Dr. Bach on trach tubes: Four out of five people who get a trach will die because of the trach. Problems include mucus plugs, development of a fistula (hole) between the esophagus and trachea (windpipe),

and granulation tissue (new connective tissue and capillaries that form on the surface of a healing wound) around the trach that bleeds when the trach is changed. The tube itself can puncture the windpipe or trachea, or even an artery. People with trach tubes also carry many bad pathogens, so it is not surprising that people with trachs have a greater number of serious infections than those who use noninvasive ventilation.

Trach tubes should be removed in those who can speak and swallow food and can cooperate and communicate.

Dr. Bach on CO₂: Too much CO₂ in the blood causes acidity just like CO₂ causes acid rain. Some CO₂ is needed to trigger the brain to tell muscles to breathe, but too much CO₂ can cause confusion, excessive sleepiness, a coma and death. Most labs do not measure end tidal CO₂ but do painful arterial blood gases which can make people hyperventilate from the pain. Painless end-tidal CO₂ is actually much more useful.

Dr. Bach on oxygen use: It's a terrible mistake for polio survivors (without lung diseases) to use oxygen. Oxygen use turns off the drive to breathe, and causes the CO₂ levels to rise. Any polio survivor who has respiratory problems, sees a physician and is sent home with oxygen will be back for treatment of pneumonia or respiratory failure sooner than if they had not been treated at all. The problems that polio survivors have are weak muscles and extra secretions, and there are solutions for both, i.e., the treatment is either assisted ventilation and/or assisted coughing.

Dr. Bach on testing: Pulmonary function testing is for lung disease, not muscle weakness. What polio people need is the measurement of vital capacity, which is the largest breath one can take both while sitting and lying down. The difference between the two should be less than 7%. Other important spirometric tests include measuring air stacking ability. The needed tests are not done in pulmonary function labs and include the measurement of cough flows, both assisted and unassist-

ed. The assisted-cough flow is measured when an Ambu bag (manual resuscitator) is used to "air stack," i.e., retain consecutive volumes of air and hold it in the throat to attain the highest volume. Then pressure is put on the belly, if the abdominals are weak, to cause a cough, and the flow is measured. If the flow is more than 270 liters per minute, a polio survivor has little chance to get pneumonia during a cold, but if less, any respiratory infection is likely to result in pneumonia.

Sleep studies (polysomnography) were never meant to test for post-polio muscle weakness, but can be useful to rule out other problems, such as obstructive/central sleep apnea which is NOT the principal problem of polio survivors. If a pulmonologist sends someone for a sleep study and they have weak inspiratory muscles, they will treat the patient incorrectly. CPAP is useless for those with breathing muscle weakness, and BiPAP suboptimal particularly at the usual settings used (Inspiratory pressure of 10; Expiratory pressure of 5).

Dr. Bach on pulse oximeters: All polio survivors should have pulse oximeters to assist with the protocol to prevent pneumonia. When sick, use the oximeter to be sure it never registers below 95%. If it does, it means one of two things. One, your CO2 is high, and ventilation is needed. Two, secretions are high, and assistance with coughing is needed. If neither treatment is used, the situation worsens and when taken to the ER, oxygen is offered which often results in breathing arrest and emergency intubation, and then unnecessary tracheostomy. Remember, if this happens, people can have the tube or trach removed and be successfully managed using noninvasive ventilation. (See "Extubation of patients with neuromuscular weakness: a new management paradigm," Bach JR, Gonçalves MR, Hamdani I, Winck JC. Chest 2010; 137 (5):1033-9.)

Dr. Bach on ventilators: Ventilator use rests a weak diaphragm and weak inspiratory muscles during sleep, and the result is feeling stronger, better during the day and blood gases are better, i.e., CO₂ is

more normal. The way to rest the muscles is to use a ventilator using pressures of 18-20 cm of water, not by using CPAP or BiPAP. Remember: It is not possible to turn off the expiratory pressure on a BiPAP machine and the user cannot air stack using it. Air stacking is important to stretch the lungs to full capacity, because if the vital capacity is 50%, that means that half of your lungs are not being used and they "close down."

"All polio survivors should have pulse oximeters to assist with the protocol to prevent pneumonia."

Dr. Bach on what breathing device to use:

Many polio survivors used negative pressure machines (iron lungs, chest cuirasses, pulmowraps) in the early days, but they caused obstructive apneas and the users experienced desaturations and high blood pressure. I don't recommend negative pressure for anybody any more. I recommend the LTV® Series (CareFusion), Trilogy Series (Philips Respironics), and Newport HT50®, HT70® (Covidien) here in the United States.

Dr. Bach on nasal masks: There are hundreds of nasal masks on the market, and I recommend that people try several. If someone has trouble with the nasal mask leaking, then try an oral/nasal device such as the Hybrid™ Universal Interface (DeVilbiss Healthcare) or the lip cover Oracle™ 452 (Fisher & Paykel Healthcare), and the oro-nasal Mirage Liberty™ (ResMed Corp).

Dr. Bach on diaphragmatic pacers: A diaphragmatic pacer is completely useless for polio people because to use the device a person needs a good phrenic nerve and a good diaphragm, and if they had them, they would need no help at all.

Dr. Bach's caveat: If you can't speak or swallow, then you do need a tracheostomy tube. ■

continued from page 1

"We are usually unaware of our CO₂ level."

the oxygen we need. Or, too many alveoli may be blocked by mucus plugs from lung infection or inadequate coughing.

We are usually unaware of our CO₂ level. Many of us fatigue and breathe insufficiently off our ventilators, unknowingly allowing our CO₂ to rise to serious levels, which a CO₂ monitor would sense. If our breathing is inadequate, and our CO₂ rises too much, our alertness decreases, most often without our realizing it. As it rises further, we fall asleep, and may then proceed into a hypercapnic (high CO₂) coma, during which we simply stop breathing.

Determining the optimum range of CO₂ for a particular person is complex and requires medical expertise. With the assistance of pulmonology staff, understanding how to interpret monitoring data should be on a par with the many other technical considerations already required of ventilator users.

Emergency Room Monitoring

Emergency room (ER) staffs now often combine pulse oximeters with EtCO₂ monitoring to pick up both potential low oxygen and retained CO₂ concerns. They monitor minor surgery ventilation under conscious sedation (light anesthesia), head injury breathing, overdose breathing, COPD and asthma exacerbations. Monitoring both oxygen and CO₂ provides much more information on ventilation status without resorting to drawing arterial blood gases.

If a neuromuscular ventilator user comes in short of breath, they would most likely get a pulse oximeter put on their finger, an EtCO2 cannula slipped just inside their nose or mouth, and get put on their favorite ventilator settings with or without trach suctioning and/or supplemental oxygen, as they awaited results of X-rays and ordinary blood tests. If their problem could be resolved, the pulse ox and EtCO2 has saved them from getting blood gases drawn. If they did not improve, then they would have to consider the harder choices, arterial blood gases might be next, possible intubation for those on NIV, maybe ICU admission.

The inexpensive pulse oximeter lets us monitor our oxygen. A problem for some is how to handle a low pulse oxygen: should more attention be given to airway mucus clearance, should the vent be used more, or should oxygen be given? If too much supplemental oxygen is given, it may sate our chemoreceptors and reduce our drive to breathe, causing a toxic rise in our CO₂. This is why oxygen use has to be so carefully considered with neuromuscular ventilation needs.

EtCO2 machines range in size from small handheld units the size of a paperback book meant for spot checks in an ER, to large multichannel ICU recorders with printers that may include up to a dozen monitored parameters. There are many companies manufacturing these units, including Philips Respironics, and there is an online aftermarket for used equipment. Cost is in the \$1000 to \$5000-plus range depending on the complexity of the machine. Philips Respironics even has a smaller transcutaneous capnographer which does not have a cannula to pick up gas for analysis, but rather a pulse ox/ CO2 combined sensor that attaches to open skin with a gel interface.

For serious ventilation management, it would be ideal to have one of these EtCO₂ monitors available as an adjunct to the pulse oximeter, but the high cost at this time is a problem. At present, there does not appear to be a simple, inexpensive drugstore version of an EtCO₂ monitor.

Although the EtCO₂ interpretation might seem complex at first, it is no more so than the many considerations already required for ventilator users. For those on part-time ventilation, awareness of CO₂ retention would alert that more ventilation is required. For those already on full-time ventilation, monitoring EtCO₂ would alert for inadequate ventilation from a variety of reasons, such as the onset of a new respiratory infection, increasing heart failure or a need for machine readjustments.

Meanwhile most of us will have to rely on our pulmonologist doing routine blood gas analysis for PCO₂ and leave the EtCO₂ monitor encounters for our trips to the ER.

Eighth Educational Conference Call

Wednesday, June 26, 2013 at 1:00 pm CT

Protecting Every Breath and Improving Patient Comfort: ResMed's S9s, the Stellar and Interfaces

presented by

Michael Madison, RRT, MBA, Sr. Portfolio Manager, Respiratory Care SBU, ResMed Corp.

Reservations are required to be on the call. To reserve your spot, contact info@ventusers.org. Reservations are on a first-come, first-served basis.

Past presentations are online at www.ventusers.org/edu/confcalls.html#pas

Looking ahead: Ninth Educational Conference Call is scheduled for Wednesday, July 31st at 1:00 CDT. Polio survivor pediatrician discusses challenges of ventilator use.

Do you have suggestions for other topics? If so, please send them to info@ventusers.org.



May 31-June 3, 2014 (Saturday-Tuesday) is the date for Promoting Healthy Ideas: PHI's 11th International Conference to be held in St. Louis, Missouri. The needs of IVUN's Membership will also be included in the program. If you have topics you'd like discussed, please send them to info@ventusers.org.

Watch www.ventusers.org and our Facebook page for updates on our plans. ■

From Around the Network continued from page 2

www.who.int/influenza/human_animal_interface/influenza_h7n9/en/index.htm

The Middle East Respiratory Syndrome Coronavirus (MERS-CoV), another new viral outbreak, was first reported in Saudi Arabia last year. It has infected 55 people and claimed 31 lives, mostly in the Middle East and Europe. No cases have been reported in the United States. People with MERS-CoV developed an acute respiratory illness with symptoms of fever, cough and shortness of breath. Transmission was through human contact. The CDC has developed a test for MERS-CoV. www.cdc.gov/coronavirus/mers/overview.html

Not yet a Member?

Join IVUN for just \$30 a year (Subscriber Membership) and receive your own copy of *Ventilator-Assisted Living* via email six times a year (February, April, June, August, October and December), plus six *IVUN Membership Memos* via email. For \$55 (Subscriber Plus Membership), join IVUN and PHI and also receive *Post-Polio Health* in print four times a year (February, May, August, November) and eight *PHI Membership Memos*.

You can join online at http://shop.post-polio.org or send or fax (314-534-5070) this form to: Post-Polio Health International, 4207 Lindell Blvd, #110, Saint Louis, MO 63108-2930 USA. Questions? 314-534-0475.

□ \$30 Subscriber

Ventilator-Assisted Living (bi-monthly via email)

□ \$55 Subscriber Plus
Both Ventilator-Assisted Living (bi-monthly)
AND Post-Polio Health (quarterly)

Name	
Address	
	State/Province
Country	Zip/Postal Code
email	
Phone (include area/country code)	
I am enclosing a check for \$_ payable to "Post-Polio Health	
Please charge \$	to this credit card:
☐ VISA ☐ MasterCard ☐ Discover	
Card No	Exp. Date
Name on Card	
Signature	

Inside Ventilator-Assisted Living

Vol. 27, No. 3, June 2013

Demystifying End Tidal CO₂ ... 1 From Around the Network ... 2

IVUN's Fifth Conference Call: How Polio Survivors Can Avoid Tracheostomies ... 3



CareFusion 866-752-1438, www.carefusion.com

The LTV® Series ventilator product portfolio from CareFusion gives patients portable advanced care ventilation in the home and at a post-acute care facility.

At 14.5 pounds and roughly the size of a laptop computer, the LTV Series ventilator features complex ventilation configured for convenience and mobility. CareFusion also offers the ReVel™ ventilator for portable ventilation on the fly. Weighing only 9.5 pounds and used for pediatric (> 5 kg) to adult patients in the home and hospital setting, this ventilator provides powerful technology to support you through the continuum of care.



CareFusion LTV Series Ventilator

RESMED

800-424-0737, www.resmed.com

Now you can provide intelligent air through iVAPS, ResMed's intelligent Volume-Assured Pressure Support. A unique technology featured in the S9 VPAP ST-A, it adjusts to a patient's respiratory rate, targets alveolar ventilation and automatically adjusts Pressure Support as needed to accommodate each patient's unique needs, even as their disease progresses.



S9 VPAP ST-A with H5i humidifier and Quattro FX full face mask

PHILIPS

RESPIRONICS

800-345-6443, www.respironics.com

Philips Respironics is dedicated to helping caregivers establish better sleep and breathing for millions of people worldwide. We develop solutions to encourage long-term compliance with therapy.

Wisp minimal contact mask – gives users a natural fit, an open field of vision, and is quick and easy to adjust with a superior seal for a restful night's sleep.



Wisp



800-634-5397, www.passy-muir.com

The Passy-Muir® Swallowing and Speaking Valve is the only speaking valve that is FDA indicated for ventilator application.

It provides patients the opportunity to speak uninterrupted without having to wait for the ventilator to cycle and without being limited to a few words as experienced with "leak speech." By restoring communication and offering the additional clinical benefits of improved swallow, secretion control and oxygenation, the Passy-Muir Valve has improved the quality of life of ventilator-dependent patients for 25 years.



PMV® 007 (Aqua Color™)