

VENTILATOR-ASSISTED LIVING

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“My Goal Now Is to Live ...”

David LaCour, Lawrence, Kansas

I was 42 years old, separated from my wife and children. At 178 pounds, I was in good health. I worked for a construction company as a steel worker. I was comfortable working with heights. My two daughters lived with their mother in Washington. I planned to go see them for the Thanksgiving holiday, but on November 22, 2009, my life changed.



David LaCour and his wife, Laurie

We had been working on a building for a dog food plant in Sabetha, Kansas. I must have stepped in the wrong place on the roof. I fell through, and my leg caught on a piece of conduit turning me head first going down. I fell 22 feet, landing on my head and left shoulder, breaking my spine at the C-2 level. I was told a woman acting rapidly used a defibrillator on me saving my life.

I regained consciousness one time and was told I had been in an accident, and we should arrive at the hospital in Topeka, Kansas, about 75 miles away, and that we should be there in about 12 minutes.

My ex-wife told me while I was there she was talking to me and noticed that I was not breathing. She told a caregiver, but was not believed. She told a second worker who checked for breathing. I was coded right in front of my ex-wife and two daughters. They all feared I would die right then and there.

The next time I remember I was in Lincoln, Nebraska, at the Madonna Rehabilitation Hospital. I was heavily medicated and was unsure if I was dead or asleep for the following six months. My ex-wife explained to me that I was paralyzed from the neck down, but I did not believe her right away.

When it began to sink in that she was telling the truth, I was certain of my goal. I would get well enough to go home as soon as possible. I would kill myself when I got home. I did not believe I could live my life in this condition. It wasn't long before the realization set in that it was not possible for me to do this unthinkable thing without help.

The support I received from my ex-wife and my daughters changed the way I thought about things. I decided to live because of them. This started a long rehabilitation process that was filled with unbearable pain. My ex-wife told me about times I was in so much pain, I pleaded with God to “take me now. I cannot take it. It hurts too bad.”

There were so many disciplines for my rehabilitation: speech therapy, wheelchair therapy, physical and occupational therapy. I had to learn to talk again, how to eat again, differently than I used to. This was extremely difficult for me. The persistence and caring of the staff at Madonna Hospital made it bearable. I was there a total of four months before transferring to Kindred Hospital in Kansas City, Missouri. I continued therapy while there over the next three

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Judith Fischer

Judith Fischer Retires

After more than four decades of service, mainly as a volunteer, to Post-Polio Health International and its predecessor organizations, Judith Raymond Fischer is retiring as IVUN's Information Specialist, the last in a series of positions she has filled over the years.

Fischer became involved with the organization, which published the *Rehabilitation Gazette*, in the late 1960s when it was coordinated from the Chagrin Falls, Ohio, home of founders Gini and Joe Laurie. Gini Laurie continued the work after moving back to St. Louis, and Fischer moved to St. Louis in 1984 to become the organization's first executive director. With Laurie, Frederick M. Maynard, MD, and D. Armin Fischer, MD, she co-edited the first edition of *Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors*.

Fischer helped Laurie coordinate the International Polio and Independent Living Conferences and began publication of *IVUN News* (now *Ventilator-Assisted Living*). She resigned as executive director in 1987 when she married Dr. Armin Fischer and moved to southern California, where she continued to edit the publication for ventilator users until 2005.

Since then, as IVUN's Information Specialist, Fischer has edited the *Resource Directory for Ventilator-Assisted Living*, compiled the *Home Ventilator Guide*, and contributed "From Around the Network" information for *Ventilator-Assisted Living*. This regularly featured column provides readers with the latest data on new products and services, and it has become a trusted source for medical news of interest to ventilator users and for accurate information on government policies and disability issues. Her network of contacts has also been the source of many informative first-person stories about ventilator users. She also has served as IVUN's liaison with the Home Care NetWork Steering Committee of the American College of Chest Physicians.

"Judith has been a strong advocate for IVUN and all patients with chronic ventilator needs," said Nicholas S. Hill, MD, Chief, Pulmonary, Critical Care & Sleep Medicine, Tufts Medical Center, Boston, Massachusetts. "You've certainly gained my admiration for your commitment and your thoughtful approach to the many challenges we've all faced."

Joan L. Headley, who succeeded Fischer as executive director, said, "IVUN is grateful for Judith's many contributions over the years. She has been a valuable friend and resource for me, and I know I can depend on her wise counsel to IVUN when needed."

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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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International Ventilator Users Network (IVUN)

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months, before transferring to Grandview Healthcare Center in Oelwine, Iowa.

I spent the next 18 months at Grandview, but while there, I temporarily was flown to New Jersey, under the care of Dr. Matthew Kaufman at the Institute for Advanced Reconstruction in Shrewsbury. Dr. Kaufman performed a bilateral phrenic nerve stimulating implant. This allows an outside device to contract my diaphragm and with practice will allow me to breathe without a ventilator for periods of time. I spent about six weeks at the Christopher Reeve Rehab Center in New Jersey before flying back to Grandview.

I was discharged home on September 14, 2011. I live in Lawrence, Kansas, now. I have a nurse 24/7 to help with care and monitor equipment. I use the vent 24/7, but hope to increase time on the breathing pacer (Phrenic Nerve Stimulator). I currently use the pacer three hours daily and can stop using the vent a few minutes at a time. There are examples of those using the breathing pacer who have been able to not need the vent except overnight.

They told me my life expectancy is nine years. My goal now is to live beyond that prediction. I've had many different types of caregivers and been neglected and even abused at times. There are caregivers whose passion for what they do that can only be compared to that of a saint. Those are the caregivers who give me hope for a future.

My biggest obstacle is the bureaucracy of the workers compensation insurance.



David LaCour (first row, far left) with teammates at Haskell Indian Nations University, Lawrence, Kansas, in 1986.

I will reach my goal and beyond to make sure that the system does not get off too easy for this treatment.

My only option for transportation has been ambulance service, United Transportation in Lawrence, and a friend and neighbor with a vehicle modified for wheelchairs. I am making arrangements to purchase a vehicle that can be modified for my use.

I would like to connect with others in similar circumstances, to give and receive support and to exchange information about other resources. Email me at catfishhead67@gmail.com. ■



Laurie LaCour with daughters Loni and Lucinda LaCour.

Dr. Braun Answers Ventilator Users' Questions



Norma Braun, MD

Norma M.T. Braun, MD, FACP, FCCP, Ombudsman, Clinical Professor of Medicine, College of Physicians & Surgeons, Columbia University and Senior Attending, St. Luke's-Roosevelt Hospital, Department of Medicine, Division of Pulmonary/Critical Care/Sleep, New York City, answered questions submitted by ventilator users.

Question: *My physician told me it is time to switch to a volume ventilator. I use a ResMed VPAP™ III (Variable Positive Airway Pressure). So, I have been using pressure. Why would he think I should switch to volume?*

Dr. Braun: The person to best answer the question is your physician. But, he is probably suggesting a different ventilator because you are changing in some way. What happens as we age? Our joints become more rigid. It takes more force to alter range of motion, and in this case, the chest cage. You may need more pressure. (Note: Adding pressure causes the nose and mouth to dry out, and can mean more leaks and less air getting to the lungs.) I suggest you ask your physician specifically what he observed. Are your blood gases signaling that a change is needed? Do you not sleep at night? Are you more and more tired during the day? Are you less sharp? Do you have trouble answering questions? Do you doze during the day? These are a few indications that your current settings aren't working for you anymore.

It is interesting that I, as all people do, need different amounts of air depending on what I am doing. I need more air if I am walking fast than if I am seated in a chair. For those who use a vent, the amount of air they receive is an average amount that doesn't fluctuate. Vent users' needs change based on what they are doing, where they live, how old they are, and changes in scoliosis, for example.

There is another reason your physician may want to switch your vent and that has to do with Medicare or insurance coverage. "Pressure" devices are also called RAD (respiratory assist devices) and after 13 months, the machine is yours,

and you no longer receive respiratory therapy services or third party payment for them. In my opinion, most polio survivors' conditions require more attention, and those services are always available with a volume vent. I also think that many polio survivors need two ventilators – one at the bed and one for the day's activities. For some, that means two different types of machines. Some machines are smaller and lighter and easier to move.

Question: *Can you clarify the difference between a volume ventilator and a pressure ventilator?*

Dr. Braun: A volume ventilator is set to deliver a specific volume of air with each breath, e.g., 600 cc. A pressure vent is set to deliver a constant specific pressure and the amount (volume) of air may vary.

Question: *Vent users are told to "check your settings." How is that done?*

I can tell you what I do. Since I work with home care companies that listen to me, I fax or email a prescription and ask them to go to the home and run two tests. One, check their oxygen level in the position in which they sleep. Secondly, check the end-tidal CO₂ (the level of carbon dioxide released at the end of expiration).

The other important thing they do is to ask patients how they feel. Asking the patient "How do you feel?" is exquisitely better than any test. Based on the information, we make some adjustments. If it doesn't feel right, we go back and make more adjustments. Then we do an overnight test in the home from which I can obtain from the computer printout the following: oxygen levels, CO₂ levels and pulse rate. The only thing I don't get is sleep cycle, but the patients can tell me how they slept. With this I have a pretty good idea if the changes we made were adequate. I may choose to do a formal test in a sleep lab that can do an EEG and tell me their sleep cycle. I rarely have to do this, though. ■

Simple Solutions

In IVUN's seventh conference call, polio survivor and ventilator user Nancy Baldwin Carter, Omaha, Nebraska, shared how she solved problems she has encountered by inventing simple devices.

Carter has neck muscle weakness and needs assistance in keeping her neck up. Her adjustable "chin crutch" assists her in breathing, swallowing and speaking. The base is a red rubber ball that prevents the chin crutch from sliding around and the top is a block of wood that is padded and covered with sheepskin. The device is placed under the back of her right jaw but does not hold her jaw shut. "It feels like a little shelf that holds up my head and opens the passageways." She uses it most of the day and can adjust its length, and she uses it all night long with her mask.



Typical headgear is too heavy and can interfere with wires from spinal surgery. The best solution for Carter is taping a stripped-down nasal mask (Breeze) to a plastic head band that provides stability. The device weighs 3.5 ounces.



Nancy Carter and her "chin crutch."

This sketch describes the setup that allows Carter to use her arms, which are non-functioning due to polio. The slings attached to her back brace are made of leather and positioned so her arms touch her sides, the position in which she can use her arms. The device is designed so there is no weight on her shoulders. ■



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Presentations from all Educational Conference Calls are posted at www.ventusers.org/edu/confcalls.html#pas

The Road to the RTX

Carol Purington, Colrain, Massachusetts

The journey started on June 1, 2012, when I received a letter saying that the machine that powers my Porta-Lung, the NEV-100, was being discontinued at the end of the year. I needed to find a replacement for something I use twenty or so hours a day. I was shocked. I'd been told that the NEV-100 was being phased out for some users but not for those, mostly polio survivors, who rented it directly from the manufacturer. Very bad communication on someone's part!

My primary care physician was sent a similar but not identical letter, in which two options were offered – switch to positive pressure ventilation (PPV) or use the Hayek RTX (www.unitedhayek.com/products), apparently the only negative pressure ventilator on the market that will operate the Porta-Lung. (Briefly, PPV blows air into the lungs through the nose or mouth via an interface or a trach. Negative pressure ventilation uses a chamber, e.g., iron lung, chestshell, Porta-Lung, to create a negatively pressurized area around the torso, causing air to be pulled into the lungs.) In my case, the NEV-100 is used to create the negative pressure.

I've used negative pressure ventilation for 60 years and didn't like the idea of changing to PPV. My primary concern is about having to use a mask or nose piece in the middle of a serious respiratory infection, when having air pushed through my throat sometimes irritates it so much that the airway temporarily closes, which is very frightening.

During this past year there have been occasions when I wondered whether I really would have to give up on negative pressure ventilation (NPV). PPV is now

much more widely used than NPV, which means it's what the medical community is familiar with and what manufacturers develop and sell. But so far converting to PPV hasn't been necessary.

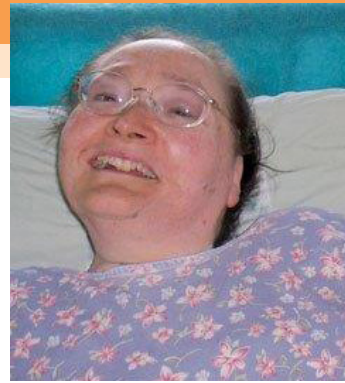
I began almost immediately to research the Hayek RTX after recalling an article in *Ventilator-Assisted Living* (October 2010, Vol. 24, No. 5). I also found another NPV ventilator that sounded promising, an Italian-made unit called the Pegaso V. No one seemed to know much about the Pegaso V because it is not available in the United States. (Note: Pegaso V is looking for a U.S. distributor having received permission to market in this country.)

Back to the Hayek. To get my hands on a trial RTX, I had to work through various medical and insurance forms. Completing that process took until November. In the interim and after several detours, I obtained the newer Porta-Lung, which is in short supply, too. I would have lost my way without much advice and assistance from family members.

Finally, on December 13, a Hayek respiratory specialist from Philadelphia brought an RTX to the house. He brought three sizes of the Hayek chest shells, none of which fit. It actually was a good thing because we discovered that the RTX can work with my familiar chest shell.

The RTX provides a different breathing rhythm, jerkier than I'm used to, but I knew I could adjust. I also tried the RTX with the Porta-Lung and found that it couldn't deliver the same readings that the NEV does. The specialist said that some RTX users find they do okay with the RTX producing lower readings than they are used to with NEV. This was not very confidence-inspiring.

The RTX is significantly louder than the NEV. That's a serious problem for me because I have a soft voice, and



Carol Purington

Carol Purington is an award-winning haiku poet who has published eight books of poetry. She is the seventh generation of her family to live at Woodslawn Farm, a dairy farm in the Berkshire Hills of Massachusetts. She contracted polio in 1955 at age 5 on her first day of grade school.



▷ also because I use a voice-recognition computer system that doesn't deal well with environmental noise.

We decided that before I made a commitment to the RTX, I needed to have tests done to compare oxygen and carbon dioxide levels with the RTX/ Porta-Lung and the NEV/Porta-Lung. Learning what equipment was needed, figuring out how it could be brought to the house, arranging to have a respiratory therapist involved, finding out how to get the information from the equipment to my pulmonologist's computer – all of these activities took until May. The tests were completed by mid-June, and I received my pulmonologist's assessment in July.

Briefly, the RTX ventilates me at least as well as the NEV. So now I know that I have to work with the RTX, at least for the immediate future. And, that I can!

Meanwhile, I will do my best to be flexible and patient. Many family members are thinking about solutions to the noise issue. Unfortunately, simple ways of reducing noise also impede the needed movement of cooling air through the unit, which can cause overheating problems.

I wish that the NEV will again become available, but I can't rely on that. I would like to network with other NEV users so we can compare our situations and solutions. Email me at carol.purington@gmail.com. ■

IVUN's Tenth Educational Conference Call

Wednesday, August 28, 2013 at 1:00 pm CT

Biphasic Cuirass Ventilation

presented by
Gary Mefford, Vice President, Hayek Medical

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.

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

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