Ventilator-Assisted Living

Fall 2007 Vol. 21, No. 3

www.ventusers.org

# Air Travel to India

Padma Varanasi, Pasadena, California, padma.varanasi@jpl.nasa.gov

Padma's father, Narayana

After living in the US for a long time, my parents, who are semi-retired in India, spend six months in India (in the fall) and six months in Washington, DC, and California (usually in the spring when it is hot in India). My father was diagnosed with ALS when he was in the US in June 2006. He wasn't given the option of using noninvasive ventilation (NIV). The ICU physicians scared us with their prognosis that eventually he would need a tracheostomy and that NIV wasn't possible in his case. I wish we had been more knowledgeable at the time so that we wouldn't have been cornered into the trach decision. My father uses the LTV®950.

My father wanted to return to India to say goodbye, and my sister and I accompanied him and my mother last September. Traveling with a ventilator requires much preparation. When I decided to help my parents return to India, I contacted many people for advice and suggestions. All were most helpful and the trip, despite minor glitches, was a success.

We booked flights on KLM Royal Dutch Airlines, owned by Northwest Airlines (NWA), from Dulles Airport to Amsterdam, then from Amsterdam to Hyderabad on September 11, 2006. We confirmed with the KLM medical desk that all was okay and ready to travel.

After we boarded, we were informed that no oxygen had been ordered for my father. They had a wheelchair, but no oxygen. Luckily, KLM airlines always carries $O_2$ but for use with a nasal cannula, not with a vent. When my dad needed oxygen during the long flight to Amsterdam, we put the nasal cannula on the trach.

Later we learned that the error was made by NWA, which handles all travels on NWA and KLM from the USA. NWA booked our flights and ticketed us in a hurry and didn't follow through with KLM's medical desk. (I have since filed a complaint against NWA with the US Department of Transportation.) The KLM flight attendants and pilots were very accommodating and apologetic. They faxed information to the medical desk, and everything was ready for my father when we arrived in Amsterdam.

My sister, my 70-year-old mother and I had been trained in trach and vent care. In order for my parents to rest, my sister and I didn't get a wink of sleep, attending to my dad. We knew how to operate the vent, suction machine and PEG tube feeding. I had persuaded my dad to get the feeding tube before the trip, because he was losing weight due to swallowing problems. The flight attendants didn't know what to say.

When we landed in Amsterdam, a wheelchair was brought to the gate,

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IVUN
International Ventilator Users Network

An affiliate of 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.*

# *Ventilator-Assisted Living*

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*Special thanks ..*

Judith R. Fischer, MSLS

## *How to contact IVUN*

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***To be sure you receive email updates from PHI and IVUN, set your spam filters to allow messages from info@post-polio.org and info@ventusers.org.***

# *Inside this Issue ...*

Pages 1 and 3

### Air Travel to India

Padma Varanasi of Pasadena, California, writes about the trip she orchestrated from the US to India for her parents. Her father, who has ALS, uses trach positive pressure ventilation and a PEG tube. The article is a thank you to all who helped her make the arrangements, and an encouragement to others who are reluctant to try post-9/11 travel.

Pages 4 through 7

### Renting your vent? What would you do if you suddenly owned it?

IVUN is celebrating its 20th anniversary this year, and we have many long-time Members who let us know what's happening in their world. IVUN heard from several ventilator users who ran into obstacles when their insurance companies bought their vents. Alan Fiala's story, which may be unique, points out the frustrations of maintaining ventilatory equipment. This article, too, is meant to thank those who help resolve problems of individual vent users and to enlighten those who can do something about the confusion.

Pages 8-10

IVUN Information Specialist Judith R. Fischer once again collected the latest news about equipment, the manufacturers, and reference materials for health professionals and ventilator users.

Maria Mastracchio, a ventilator user from Quebec, comments on her impressions of a recent home mechanical ventilation meeting, which is followed by the "Calendar" of future meetings. Having a meeting? Send the details to info@ventusers.org. We will also post it on our new website – www.ventusers.org.

Pages 11 and 12

### Celebrating its 20th year, IVUN announces its new website – www.ventusers.org.

IVUN is a Membership organization whose work is underwritten by its dedicated supporters acknowledged on page 12. We invite you to check out www.ventusers.org and become a Member.

**Take Charge, Not Chances** is the descriptive name of the portfolio of four documents developed by the Ventilator Users' Medical Emergency (VUME) Project. The documents will be available soon online at www.ventusers.org at the bright red and blue Take Charge, Not Chances logo. Ventilator users who do not have access to the Internet may request a copy by calling 314-534-0475 or mailing to IVUN, 4207 Lindell Blvd, #110 , Saint Louis, MO 63108-2930.

*–Joan L. Headley, Executive Director*

## Air Travel to India

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and my dad was wheeled (although he can still walk) to the medical desk which we were told was 45 minutes away, but in reality was only five minutes. There they had a room with an O2 concentrator for my dad. After resting for four hours, we began the next leg of the journey to Hyderabad.

Even though the flight was more than eight hours, my father was so determined. All went well when we arrived in India. He was received by his siblings and happy to be in familiar surroundings.

In Hyderabad, we went to Apollo Hospital and met with the pulmonologist whom I had already contacted. After he examined my father and read the reports we brought with us, he immediately formed a team with a neurologist, an ICU physician and a general physician. We admitted my dad to the hospital, so all tests could be done in one day. To my surprise, the hospitals and doctors are super. The “care” in the word “healthcare” really means something.

We took all the supplies we could from the US but everything we needed is available in India. I arranged for a caregiver to stay with them from 8:30 am–6:30 pm. My mother is fully trained, but she needs to rest and can run errands while the caregiver is there.

My parents seem content and at peace in India, where there are noises all day, and someone stops by – the maid, milkman and watchman. Seeing my mother so independent and in control also gives my father confidence. It was hard for me to part, but this is what they seemed to want.

The journey was a tremendously satisfying learning experience. I returned to the US from India after spending two weeks. I’ve never seen my father with tears in his eyes until I said, “Goodbye.” I’m grateful for everyone’s support in making my parents’ dream come true. ▲

**Mobility Air Transport (MAT)** is developing a nationwide air taxi service made up of aircraft modified specifically for passengers who use wheelchairs. Flights will be priced per person with fares comparable to those published online by the major air carriers. Smaller regional airports will be used. Ventilator users will be able to bring their vents onboard. Oxygen will be available at reasonable rates. A nonprofit organization, MAT’s mission is dedicated to making air travel more accessible, convenient, and comfortable for people with impaired mobility. These flights are NOT for emergency medical flights requiring special medical equipment, supplies or medical assistants on board. www.emtlaser.com/mat

## Air Travel in India

Because air transportation is easier and cheaper within India, more people with disabilities are flying. On July 25, 2007, the Office of the Director General of Civil Aviation, New Delhi, issued a “Draft Civil Aviation Requirements (CAR) Section 3 Series 'M' Part I -- Carriage of Physically Challenged Passengers by Air.” The requirements are effective August 15, 2007. www.dgca.nic.in/misc/draft%20cars/D3M-M1%20(R1%20draft).pdf

Ghulam Nabi Nizamani (gnn_sgr@yahoo.com) and other advocates at Disabled Peoples' International (www.dpi.org) report that the policy is not being followed and that many Indian airlines still insist on a “fitness to fly” certificate from persons with disabilities, and one airline assesses an additional charge if a person has a disability.

Ventilator users should note that the policy as written requires medical clearance when a passenger “would require medical attention and/or special equipment to maintain their health during the flights.” This clearance is to be obtained from the passenger’s physician or through the medical departments/advisors of all carrying airlines. ▲

# Renting your vent? What would you do if you suddenly owned it?

Alan Fiala, Falls Church, Virginia, fialaalan@earthlink.net

IVUN: You have discovered some serious complications that arise from owning your own vent. Before we discuss this, tell us what vents you own and how you came to own them.

FIALA: I own two vents: I own a PLV®-100, made by LIFECARE, now Respironics, and an LTV®800 made by Pulmonetic Systems, that were paid for largely under my primary health insurance. As a federal employee, my primary health coverage is obtained through the Federal Employees Health Benefit (FEHB) program.

I started using a vent for sleeping in January 1985, after respiratory failure that was the most serious of some late effects of polio. The insurance company I had at that time rented several types of equipment for several years from LIFECARE, which provided both the equipment and home healthcare service. Renting has a number of service advantages, primarily the ability to change models of vent, and is currently the standard for most vent users.

At some point, my insurance company decided it was most cost-effective to buy my PLV®-100 rather than pay the monthly rental fee, which falls under the category of durable medical equipment that needs “frequent and substantial service.” Maintenance and Respiratory Care Practitioner (RCP) services were left up to me.

Around 2002 I acquired the second ventilator for updated technology, a backup, and convenience in travel, especially international air travel.

IVUN: What new considerations came with ownership?

FIALA: With ownership, I was particularly concerned about maintenance. LIFECARE offered a full coverage maintenance package with the PLV®-100 that Respironics has continued but no longer offers to new owners. For a fixed monthly fee, I get annual preventive maintenance plus a guarantee to fix any problems at no additional cost, even total destruction, as long as the pieces are retrievable, with a replacement loaner within 24 hours in the US. They also sell me masks and accessory pieces.

I could claim the monthly maintenance fee under durable medical equipment, but my insurance policy has a lifetime dollar limit, and I didn’t want to exhaust it for this, so I have been paying it myself.

When I purchased the LTV®800 through a local home healthcare company, I asked about maintenance. I was assured by the Pulmonetic representative that if there was any

## Alan’s Breathing and Ventilator History

Alan Fiala had polio in 1952 at age nine and was hospitalized for three months. It affected his mobility, caused severe kyphoscoliosis, but he was never in an iron ling. He traveled extensively during a 40-year career as an astronomer, but is now retired and travels less.

In January 1985 he was hospitalized for one week with respiratory failure. The hospital, through its respiratory services department, arranged for the ventilators and home care service. Alan’s breathing problems started as early as 1983 following a spinal fusion in 1981.

Use of rental ventilators allowed for trial of different types and models. First was a negative pressure chest cuirass for a few weeks, then the Pulmowrap for about a year, neither of which worked well enough. He moved to a positive pressure volume vent, the PLV®-100. For about five years, he used the PLV®-100 with oxygen, but from information gained at post-polio conferences and reading IVUN literature, he discontinued oxygen. He also follows the latest developments in nasal interfaces through these resources.

problem, I had only to ship it to the plant in California, and they would send a loaner to me at the same time. Unfortunately, this was never rendered in writing, and the company is now part of VIASYS, recently bought by Cardinal Health.

IVUN: What is the nature of the problem now and when did it first arise?

FIALA: The problem for me is getting service for the LTV®800, but it might be broader and extend to other manufacturers and their products. *(See page 7.)* In December 2004, I learned second-hand from Post-Polio Health International that my vent was included in a recall, but I didn't follow up on it. Neither the home healthcare company nor Pulmonetic Systems contacted me. They did not consider me to be a customer because I owned the vent and was not paying a monthly fee.

In October 2005, the LTV failed and I began a quest to get it repaired. The home healthcare company was no longer dealing with vents, and since I had not followed up on the recall, I contacted Pulmonetic's technical support directly. The representative told me that they would not accept the unit from me as an individual, because they only provide equipment and services through home healthcare companies.

I was then referred to several regional and area representatives of Pulmonetic Systems who felt no obligation to me as a customer, even when I pointed out that if I hadn't had a backup, I would have been hospitalized. The most common explanation was the soon-to-recur assertion that they were not set up to deal with individuals for reasons of "regulatory issues" and "liability." I was also warned that the unit was out of warranty, and I'd have to pay for repairs. When I asked for local companies that handled LTVs, I was referred to the same home healthcare company that no longer provided vent service!

I contacted the Pulmonetic senior clinical advisor, who helped me get service on my unit and a loaner. She also helped me get a letter of agreement to guarantee repairs for a fee on my ventilator for three years with a warranty for the first year. Getting a loaner delayed the process by over a week, because it took that long for them to find one in their network, the LTV®800 being their least-used model.

When these arrangements were finally agreed upon, their representative picked up my vent in person. From him I learned that I was considered a real oddball for owning my vent, and that less than five percent of vent users are in this situation. Most of their business is with a person who within a short time either recovers and no longer needs a vent, or dies. He said that the company tech should have accepted my unit based on the recall, that the home healthcare company is obligated to continue service for any vent it sells, and assured me I wouldn't have to pay for the portion of the service required by the recall.

IVUN: You now have agreements with both Respironics and Pulmonetic Systems. Are your problems solved?

FIALA: No. First, I have no ready access to a respiratory care practitioner (RCP). When I need a new mask that is different from a previous one, it is

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## Renting your vent? What would you do if you suddenly owned it?

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very helpful to have a trained person to pick the size and make adjustments, and provide any pieces of circuit or connectors needed.

Second, the agreement for the LTV®800 is very limited, and I am still concerned about repairs or a backup when I travel, especially out of the country. That was a primary reason for purchasing the LTV – it is lighter, has fewer moving parts, and has dual voltage capability. Under my service contract with Respironics, they will assist me in the US. If I travel abroad and need a PLV®-100 with a different voltage, they have international offices that can provide a rental unit, given enough lead time. I have taken advantage of that in at least four countries.

**IVUN:** Do you see any solution to either problem?

**FIALA:** Not yet. My pulmonologist, Brian Turrisi, MD, suggests asking another home healthcare company if they will provide occasional consultations with an RCP, but warns that their focus on authorization by a physician and payment by an insurer may be an obstacle.

I am still working on the maintenance and repair issue. Pulmonetic Systems has suggested that I subcontract with a third party and implied that their vents are so reliable that it is not profitable to maintain a repair facility. My understanding is that the monthly fee the home health companies charge is for the guarantee of a working ventilator 24 hours a day (because many people who use volume vents use them as life support), plus services of an RCP as needed.

I contacted two private companies listed in IVUN's *Resource Directory for Ventilator-Assisted Living*. The conversations were similar. Neither had ever been contacted by an individual vent owner. Both wanted to know why Pulmonetic Sytems would not offer service to me directly, and both expressed concern at the "liability" defense. Hence they were initially uncertain whether their insurers would permit dealing with me either. One company subsequently agreed to accept my unit for service if needed, and gave me the fee schedule and contact information. The other company has withheld a decision pending their becoming an authorized Pulmonetic repair facility.

My advice to others who are forced to become owners of their vents and have to search for service: be prepared to offer to pay the cost yourself up front if you need immediate service. If you think you have insurance coverage, then try to get reimbursement from your health insurance company afterwards. Also, have a backup unit available through separate arrangements. Make all these arrangements and contacts before you have an emergency.

My medical insurer made the decision to buy my vents, not me. Insurance carriers in general – liability for providers, payment for users – seem to affect provision of services. For a long-term user of a ventilator, ownership is far more economical than rental for whomever is paying. However, technical support should be just as easily available to an owner as it is to a renter. The original manufacturer should be ultimately responsible for seeing that it is. ▲

## Ownership Policies of Manufacturers

*IVUN contacted the following manufacturers to ask whether individuals could deal directly with them in buying and maintaining a ventilator. These ventilators are in the Medicare reimbursement category of frequent and substantial servicing (FSS).*

**Impact Instrumentation** provides for individual ownership and maintenance agreements for the Uni-Vent® Eagle™ 754. www.impactii.com

**Newport Medical Instruments** reports that they have a procedure in place for providing technical service to individuals who own the HT50®. www.ventilators.com

**Pulmonetic Systems, Inc.,** a division of VIASYS Healthcare Inc., only deals with durable medical equipment companies, not individuals, for sales and maintenance of the LTV® series. www.pulmonetic.com

**Puritan Bennett's** technical support department stated that they only deal through durable medical equipment companies. Individuals cannot buy their own Achieva® or LP10 and obtain a maintenance agreement. www.puritanbennett.com

**Respironics Inc.** does not repair its PLV®-100, 102 & 102b directly for ventilator users. Individuals are referred to the homecare company from which they purchased it initially. If a homecare dealer cannot or will not assist, Respironics Colorado may be able to help individuals depending on their insurance coverage. www.respironics.com

**VersaMed** does not sell the iVEnt201® to individuals, but only deals through a durable medical equipment company. www.versamed.com

**VIASYS Healthcare's** technical support department for Bird Products stated that individuals can own the TBird® Legacy and obtain a maintenance agreement. www.viasyshealthcare.com

**What about the new policy on bilevel devices, such as ResMed's VPAP® Series or Respironics' BiPAP® units?**
These bilevel units are considered "respiratory assist devices" or RADS by Medicare and are now in the capped rental reimbursement category. This means that after 13 months, ownership of the bilevel unit transfers from the durable medical equipment company to the vent user. (See *Ventilator-Assisted Living,* Vol. 21, No. 1, pages 4-5, *UPDATE: Medicare Reimbursement Changes Affect Vent Users.)*

**How do the new "owners" obtain maintenance and repairs for RADS?**
Diana Guth, (diana@hrcsleep.com) owner of Home Respiratory Care, Los Angeles, California, advises the following. "A durable medical equipment company will send the device to the manufacturer for repair. Medicare will usually pay for the repair and rent another device for a month during the repair period. The exact wording is 'If the expense for repairs exceeds the estimated expense of purchasing or renting another item of equipment for the remaining period of medical need, no payment can be made for the amount of the excess. Repairs of rented equipment are not covered.' "

For complete details, check out:
www.cms.hhs.gov/MLNMattersArticles/downloads/MM5461.pdf and
www.noridianmedicare.com/dme/
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## Rosie's Story

Rose Marie Benecke, Wildwood, Missouri, eromni@aol.com, user of a PLV®-100 for 17 years, due to childhood polio, owned her ventilator, because her insurance company chose to buy it. After retirement, her insurance was transferred to Medicare.

In early 2007, her physician advised her to rest using the vent a couple of times a day for an hour, with a mouthpiece instead of the mask she wears at night. Because she owned her vent, she was not connected with a healthcare company and contacted Medicare directly. Medicare refused to pay for the mouthpiece, because according to their records she didn't have a ventilator. She paid for the mouthpiece out-of-pocket.

Concerned about the situation, she discussed it with her physician, who wrote a prescription for a new ventilator, the LTV®800. Benecke likes her new vent although it took awhile to get used to the different sound. Currently, she is using a nasal mask made by Healthdyne Technologies (1990) that she found in the box of old interfaces and tubing she stockpiles under her bed.

This ventilator is reimbursed by Medicare under the frequent and substantial servicing (FSS) category, with monthly rental payments going to her home healthcare company, which is required to provide periodic monitoring of the equipment and settings, a promise of a functioning machine at all times, and assistance with obtaining accessories. The payment will continue as long as she medically needs the vent.

# From Around the Network

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

Mirage® Quattro™

Mirage® Liberty™

## New Interfaces

**Mirage® Quattro™**, a new full face mask from ResMed, is similar to the Ultra Mirage®. The Quattro's newer design reduces possible discomfort at the nose and chin. Dial-in settings enable a comfortable fit and seal. www.resmed.com

**Mirage® Liberty™**, also from ResMed, is a combination mask that offers nasal pillows with a dual-wall mouth cushion. Easy to clean and to take on and off. User is able to wear glasses for unrestricted vision. www.resmed.com

**V2™**, a newer model full face mask from Hans Rudolph, Inc., is now available. The V2 is a one-piece completely flexible face mask that fits below the chin. New interior sealing flanges conform to facial contours. www.rudolphkc.com

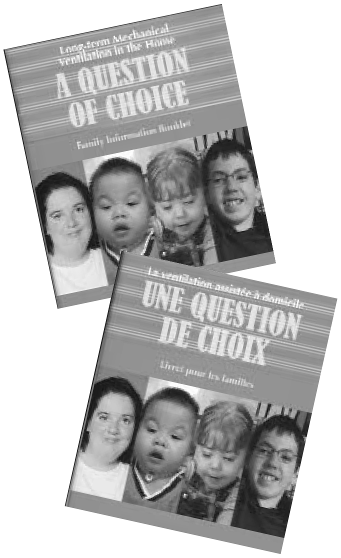
**Bravo™ Nasal Pillow System** from TeleFlex Medical, offers three sizes of pillows and headgear with four points of adjustability. Contoured reservoirs enable multiple sleep positions. www.teleflexmedical.com

## Custom Mouthpieces in Canada

Connie Brooks, University of Alberta in Edmonton, writes, "Several dentists in Alberta, Canada, make custom dental mouthpieces. They cost about $300-700 Canadian, but they last for several years. The province of Alberta covers the cost. I am dealing with Adams Denture Clinic in Ponoka, Alberta, 403-783-6665, and the University of Alberta Hospital Dental Clinic in Edmonton, 780-407-6854." For more information, contact Connie.Brooks@gov.ab.ca.

## Sip (Mouth Intermittent Positive Pressure) Ventilation

Louie Boitano, RRT, Josh Benditt, MD, and the team at Northwest Assistive Breathing Center in Seattle, Washington, produced a new edition of their *Resource Manual on Noninvasive Mechanical Ventilation* that details ventilator setups for the "sip" or mouth intermittent positive pressure ventilation system. To request a manual, email boitano@u.washington.edu.



Long-term Mechanical Ventilation in the Home
A QUESTION OF CHOICE
Family Information Booklet

La ventilation assistée à domicile
UNE QUESTION DE CHOIX
Livret pour les familles

## A Question of Choice

Two booklets called "Long-term Ventilation in the Home: A Question of Choice" are being distributed by Rita Troini, RRT, MA, Training and Development Consultant, National Program for Home Ventilatory Assistance (NPHVA), McGill University Health Centre (MUHC), Montreal, Quebec, Canada.

One booklet targets families; the other is written for clinicians. Both are published in French and English. Troini states, "The production of these booklets results from a specific need that was identified in a study published in 2006 (See Carnevale, F.A., Alexander, E., Davis, M., Rennick, J.E. and Troini, R. Daily living with distress and enrichment: The moral experience of families with ventilator-assisted children at home. *Pediatrics,* 117(1), 48-60.) The goal is to disseminate the actual testimonials of families ... ."

If you would like to order booklets, please contact Troini at rita.troini@muhc.mcgill.ca.

## New Model

**The Vest**®, the airway clearance system from Hill-Rom, now offers a ramping feature and Spanish language option. www.thevest.com

## Pediatric Trach Care

Matt and Melanie Dragovits are the parents of a child with a tracheostomy. They have produced a pediatric tracheostomy care video program called "Breath of Life," available for free online viewing. www.patienteducation.tv/trach_video.php

## Acquisitions and Spinoffs

**VIASYS Healthcare** is now a wholly-owned subsidiary of **Cardinal Health**, a manufacturer of medical and surgical products worldwide. VIASYS, which had acquired Pulmonetic Systems, Inc., will become part of Cardinal's Medical Products Manufacturing segment. www.viasyshealthcare.com, www.cardinal.com

**Tyco Healthcare** (recently spun off from Tyco International) is now operating as **Covidien Ltd.** Tyco's **Puritan Bennett** division, manufacturer of the LP10 and Achieva®, continues operations. www.puritanbennett.com

## Education

"**Learning Opportunities for Your Child Through Alternate Assessments.**" This booklet introduces parents to the "big ideas" contained in school improvement efforts under the *No Child Left Behind Act of 2001 (NCLB)* and the *Individuals with Disabilities Education Act (IDEA)*. It provides parents with information to help ensure that their children can benefit from these efforts. www.ed.gov/parents/needs/speced/learning/index.html

## Advocacy Effort on Behalf of Veterans

Last fall, ventilator user Sandy Stuban, Lieutenant Colonel, Retired, US Army, initiated a proposal requesting an increase in Aid and Attendance for Veterans who use ventilation fulltime. (See *Ventilator-Assisted Living,* Vol. 20, No. 3, p. 8) The American Legion joined her campaign and sent the proposal to every member of Congress.

This June, the Veterans' Disability Benefits Commission included Sandy 's proposal in a list of new benefits to be considered. IVUN wrote a letter of support asking for the increase in attendant care funds, making it possible for veterans who use vents to live at home instead of in an institution. The final decision has not been made.

## Celebrating Dr. Augusta Alba

Coler Goldwater Specialty Hospital and Nursing Facility, New York City, celebrated 50 years of dedicated service to its patients and residents by Dr. Augusta Alba on July 19th, 2007.

Dr. Alba's dedication and service to the numerous polio survivors and ventilators users around the world and to International Ventilator Users Network is legendary.

Notes of congratulation and thank you may be sent to Karen.Gooding@nychhc.org or mail a note to Dr. Augusta Alba, Coler Goldwater Specialty Hospital, 1 Main Street, Rm E3-3, Roosevelt Island, New York, 10044. ▲

Dr. Augusta Alba, Saint Louis, 2000

# Noninvasive and Home Mechanical Ventilation Conference: ICU and Beyond, Montreal, Quebec, Canada, June 22-24, 2007

Maria Mastracchio, Montreal, Quebec, Canada, inner.sanctum@sympatico.ca

As a person who uses a BiPAP® unit, attending this conference was an enlightening experience. The international speakers, from England, Italy, France, as well as the US and Canada, presented an incredible overview of how physicians deal with the whole family when one member uses home ventilation. A good support system for home ventilation is extremely critical for its success.

What impressed me the most was the huge pressure put on the pulmonary doctors with limited resources to provide their patients a quality of life. Physicians, nurses and respiratory therapists asked excellent questions, discussed their frustrations, and exchanged invaluable successful experiences. Their patients are their first concern; regardless of cost, they know how to get the best for them.

The conference offered a variety of interesting topics. I was pleasantly surprised and happy to hear about “Sex and the Ventilator User: The Patient’s Perspective.” It reassured me that my married life could go on for years. It is a question of careful planning!

“The Role of Telehealth in Long-Term Mechanical Ventilation” was a fascinating presentation. Telehealth can reach many people spread over wide geographic areas. The home ventilatory program for my province of Quebec functions much more efficiently through the use of telehealth. It can also serve as a vehicle for the self-management program at McGill University Health Center to help empower ventilator users from a distance.

A precious souvenir is my conversation during the conference with Bernard Gaudon, a polio survivor from France who had his home constructed according to his requirements. His table was made for his height. He eats standing up so that he can breathe better. He uses a bilevel unit only at night.

Exhibits of ventilator equipment gave me hope that I can always get another machine at a later date. Attending the conference reassured me about the high professional quality of my respiratory therapist and Quebec’s home ventilation program.

Many thanks to the American College of Chest Physicians, IVUN, and Rita Troini, RRT, for affording me the opportunity. ▲

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## CALENDAR

**OCTOBER 4-6. ALS/MND Nursing Symposium.** Radisson Hotel, Chicago, Illinois. www.lesturnerals.org/educationalactivities.htm#nursing

**OCTOBER 20-25. CHEST 2007.** American College of Chest Physicians, Chicago, Illinois. www.chestnet.org

**DECEMBER 1-4. 53rd International Respiratory Congress of the American Association for Respiratory Care.** Orlando, Florida. www.aarc.org

### 2008

**APRIL 10-12. 8th Annual Focus Conference.** Gaylord Opryland Resort, Nashville, Tennessee. www.foocus.com

## IVUN Celebrates 20th Anniversary

International Ventilator Users Network (IVUN) celebrates 20 years as a worldwide resource for ventilator users, respiratory health professionals, and ventilator manufacturers. Created in 1987, IVUN's goal was to reach more people whose health conditions cause them to use assisted ventilation long-term.

Mickie McGraw writes, "Time and again, IVUN and the people behind it have been my primary link to the resources I need to live a quality life *independently.* Permanent disability does not mean static disability – my body and the world around me is ever-changing, and IVUN helps me access the resources I need to adapt and cope with these changes. Whether it's for information about the newest positive pressure face mask or help and encouragement to get through surgery requiring a general anesthetic, IVUN has been there for me and I'm eternally grateful!"

### IVUN's New Website – www.ventusers.org

Ventilator users and health professionals can now access IVUN's site – www.ventusers.org – directly rather than through www.post-polio.org. However, the sites are similar in design and at the bottom of every page there is a link to the other site.

The site also has a "Find" button, which will allow users to access the information they need more efficiently. Special areas include Home Ventilator Guide, *Resource Directory for Ventilator-Assisted Living,* IVUN's Ventilatory Equipment Exchange, and many articles from past issues of *Ventilator-Assisted Living*.

### *Resource Directory for Ventilator-Assisted Living* Updated Every Fall

Every fall IVUN contacts the institutions, health professionals, organizations and associations, equipment manufacturers and facilities with long-term ventilator units which are listed in its *Resource Directory for Ventilator-Assisted Living* to confirm the information. Watch for your email from info@ventusers.org in late September.

Others who may want to be listed are asked to look at the *Directory* online at www.ventusers.org/net/VentDIR.pdf. and send their contact information to info@ventusers.org.

## Join IVUN!

***Support International Ventilator Users Network's educational, research, advocacy and networking mission.***

Rates Effective 2007

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