

## Program to Coordinate Helper Teams for HMV Users in East Denmark

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In 1990, Denmark passed a law that funded two respiratory centres for individuals who needed mechanical ventilation. Respiratory Centre West is located in Århus and Respiratory Centre East is located in Copenhagen, each serving half of the country. The purpose of the centres is to provide treatment and follow-up for patients receiving home mechanical ventilation (HMV). The centres also were charged with the education and supervision of the helper teams or the individuals who provide personal assistance to the ventilator users.



Grethe Nyholm, RN

Over the last two decades, there has been an increase in numbers of patients needing HMV, such as individuals with post-polio, muscular dystrophy, tetraplegia, complex sleep apnea and children with craniofacial and neuro-metabolic disorders, causing a need for a separate system to administer the program that trains and coordinates the helper teams.

In January of 2009, a new program, headquartered in Glostrup Hospital, was started. The staff includes a supervisor, an administrator, an administrative coordinator and a nurse. As the nurse, my duties include selecting and organizing the helper team for the ventilator user, developing contracts between the helper agency and Glostrup Hospital, entering user information in a database, meeting with the teams' supervisors to match up teams with HMV users and reviewing and paying the monthly agency invoices. Since 2009, the region has saved 20 million Danish kroner (DKK) or \$3.6 million USD per year.

The goal is to improve the quality of life of Denmark's HMV users in a cost-effective way and to improve the quality of the helper teams. Today there are 121 patients in the program. The HMV users are referred to the respiratory centre from a neurologist, pediatrician or pulmonologist. At the respiratory centre, diagnostic procedures are carried out including sleep studies, blood gases and pulmonary function tests. HMV prevalence in Denmark is 22 per 100,000 population.

During 2012, 53 more HMV users will be moved to the program. Most are living in their own homes. The 2011 budget for assisting 175 HMV users is 300 million DKK (\$54 million USD). This includes education and training, salary and benefits for the helper teams and administrative costs. A team with nurses costs 3.4 million DKK (\$618,000 USD); without nurses, 2 million DKK (\$363,500 USD) per year for 24-hour care. For 2012, the budget will be 330 million DKK.

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**From Around the Network**

Judith R. Fischer, MSLS, IVUN Information Specialist, [info@ventusers.org](mailto:info@ventusers.org)

*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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*Special thanks ...*  
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*Philip Respironic's TruBlue Gel Nasal Mask*

**Home Care**

IVUN participates in the Healthcare at Home Initiative, a broad alliance of organizations representing disability groups, consumer advocates, family caregivers and companies that provide medical care and equipment. Spearheaded by the American Association for Home Care, the group urges legislators to reject budget cuts that will restrict access to the home-based services and support needed by millions of Medicare and Medicaid beneficiaries.

“While not a panacea, home-based care is a highly cost-effective part of our healthcare system that fosters quality of life and helps millions of seniors and people with disabilities to live independently in their own homes. Americans overwhelmingly report that the home is their preferred setting for receiving care.”

For more information, go to [www.aahomecare.org](http://www.aahomecare.org). ▲

## Program to Coordinate Helper Teams for HMV Users in East Denmark

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Besides living in their own home with their families, another advantage for Danish ventilator users is that hospital treatment is done in the home supervised by Respiratory Centre East.

The program contracts with and oversees an agency to provide the daily care after the ventilator user provides a profile, so the best qualified persons are hired. All the helpers are trained both in practical and theoretical knowledge at Respiratory Centre East. Each team is coached to guarantee good care. Helpers work a maximum of 12-hour shifts, and the helpers are required to be in constant contact with the ventilator user for safety reasons. Relatives cannot be employed as a helper. The helper agencies report to my team at Glostrup, and of course the patient is still seen in the Respiratory Centre.



*Hanne Birthe Bruun, 69, benefits from the Danish government program. She contracted polio as a child and has been an HMV user for more than 30 years, first with nasal ventilation, and, for the last 13 years, she has had a tracheostomy. She is an active woman and enjoys traveling with her husband to Mallorca each year.*

This program only serves the area around Copenhagen. The program has spread to half of Denmark (Region Copenhagen and Region Sjælland). ▲



## Breathing and Sleep Symposium

**Fang Han, MD**, The People's Hospital in Beijing, at the Breathing and Sleep Symposium held at the Salk Institute in La, Jolla, California, on October 29, 2011. Dr. Han, himself a polio survivor, is a sleep medicine specialist who discussed his treatment of polio survivors in China.

Other presenters included Josh Benditt, MD, on the mechanics of breathing in neuromuscular disease, Anthony De Maria, MD, on hypertension and sleep apnea, and Angela King, RRT-NPS, and Karyl Scott, RRT, who described ventilator and mask options. The symposium, held annually since 2009, was co-sponsored by ResMed and the Salk Institute. Presentations are online: [www.poliotoday.org](http://www.poliotoday.org), click on Videos. ▲

*Photo credit: Sue Lau, Polio Survivors Plus*

## From Cor Pulmonale to Getting a Second Chance

Sara Fainstein, San Diego, California, sarafain18@sbcglobal.net

**M**y husband Jaime's story with polio began in 1949 in Mexico City when he was 4 years old. The poliovirus affected his legs, right arm and diaphragm. After Jaime's diagnosis, he was hospitalized and spent some time in an iron lung. He doesn't remember all the details but Jaime has always had difficulty yelling loudly or coughing hard.

A week after having received his flu vaccine in December 2010, Jaime had what we thought was a simple cold, with some phlegm and coughing for several days. He was unable to cough up all the phlegm and became congested to the point that on the afternoon of December 23, he was so short of breath that we called the paramedics. When they arrived, Jaime's oxygen saturation level was 70 percent. He was rushed to the nearest emergency room and was placed on a ventilator. Jaime spent the next two weeks in the ICU at Sharp Memorial Hospital in San Diego where his team of pulmonologists diagnosed cor pulmonale. (See page 5.)

Given Jaime's history of polio and the probability of needing a ventilator for some time, he had a tracheotomy and was transferred to Kindred Hospital-San Diego, where he spent the next five weeks being successfully weaned from the vent and able to speak and swallow following speech therapy. At this point, he was released to Sharp Memorial Rehabilitation Center for physical and occupational therapy before he was able to come home by mid-March of 2011.

While at Kindred, Jaime was evaluated for sleep apnea, and the results of the sleep study showed that Jaime would stop breathing 40 times out

of the hour. It was recommended that he use a bilevel ventilator, but Jaime was not able to adjust to the ill-fitting hospital mask.

Jaime's situation became complicated at home because the swelling in his ankles became worse and his oxygen saturation was lower. He was re-admitted to Sharp in mid-July for a few days for stabilization and strong use of diuretics, and then spent the next four weeks at Kindred. This time the goal was to use the bilevel successfully, in order to assist his weak chest muscles, which could not get rid of the carbon dioxide that was accumulating in his system.

In mid-August, thanks to the support of the staff at Kindred and our guardian angel, Jill Minch from Sleep Data, Jaime tried ResMed's Mirage Quattro™ mask, which worked well, but irritated the bridge of his nose. He switched to the Mirage Liberty™ and uses it with a ResMed bilevel unit throughout the night.

Now Jaime looks forward to sleeping and waking up well rested so that he can continue with his physical therapy. He is one happy breather! ▲

## What is Cor Pulmonale?

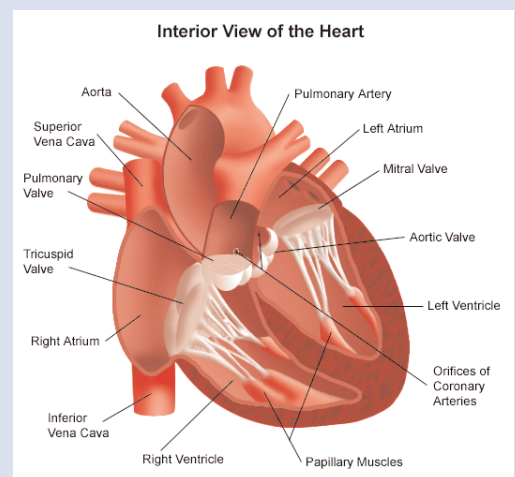
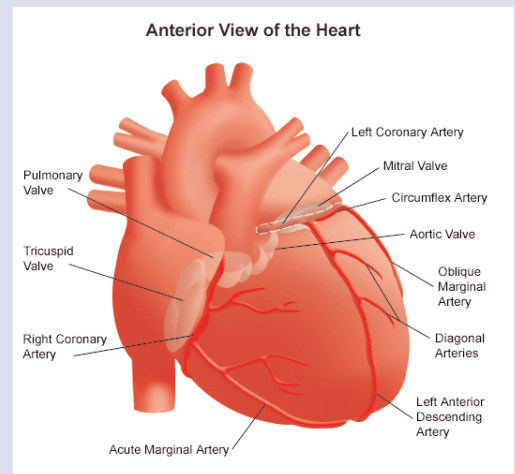
Cor pulmonale is the development of right-sided heart failure due to pulmonary hypertension. As MedlinePlus (National Institutes of Health) explains it, "Normally, the left side of the heart produces a higher blood pressure in order to pump blood to the body. The right side of the heart pumps blood through the lungs under much lower pressure. High blood pressure in the arteries of the lungs is called pulmonary hypertension. The right side of the heart has a harder time pumping blood against these higher pressures. If this high pressure is present for a longer period of time, it puts a strain on the right side of the heart, leading to cor pulmonale."

The condition can be caused by various lung conditions, but in people with neuromuscular disease or COPD, it is more often caused by low blood oxygen over a long period of time, which coupled with high carbon dioxide levels in the blood leads to hypoventilation (underventilation). Cor pulmonale is more common among people with neuromuscular disorders who also have significant chest wall involvement.

Symptoms include shortness of breath, light-headedness, chest discomfort and pain, abdominal pain due to liver enlargement, and perhaps fainting. The failure of right side of the heart causes body fluids and blood to build up, sometimes all over the body, but a big warning symptom is fluid retention in the ankles. Other signs can be abnormal heart sounds, swelling of the neck veins, and in later stages, bluish skin (cyanosis) signaling low oxygen levels.

Diagnostic tests may include electrocardiogram, chest X-ray, Holter monitoring, echocardiogram to check ejection fraction of each ventricle, and arterial blood gas tests. Diuretic treatment is usually prescribed, with perhaps a potassium supplement to replace that lost through the kidneys from the diuretic use. Prompt treatment with assisted ventilation, either with a bilevel ventilator or volume/pressure support ventilator, can reverse the condition.

Preventing the condition in the first place is key. Know the signs and symptoms of hypoventilation.



**MORE on** [www.ventusers.org](http://www.ventusers.org)

See "What is hypoventilation?."

[www.ventusers.org/edu/valnews/val17-1.html#wha](http://www.ventusers.org/edu/valnews/val17-1.html#wha)

Thanks to Josh Benditt, MD, FCCP, Medical Director, Respiratory Care Services, University of Washington Medical Center, Seattle, and Barbara Phillips, MD, FCCP, Sleep Disorders Center, UK Healthcare Good Samaritan Hospital, Lexington, Kentucky, for their review.

# Ask The Experts

**QUESTION:** *As a night-time ventilator user due to a neuromuscular condition, I need to be alert to any infection developing in my lungs or sinuses. I typically ask for and use an antibiotic at the first sign of any infection. However, I hear more and more warnings that taking these medications can result in a resistance to antibiotics. What guidance can you offer to help me (and my family physician) decide when to take antibiotics?*



**ANSWER:** *Norma MT Braun, MD, FACP, FCCP, Ombudsman, Clinical Professor of Medicine, Columbia University, College of Physicians & Surgeons and Senior Attending, Department of Medicine, Pulmonary/Critical Care/ Sleep Division, St. Luke's-Roosevelt Hospitals, New York, NY, [nbraun@chpnet.org](mailto:nbraun@chpnet.org)*

It would be helpful to know whether the questioner uses NIV or ventilates via a tracheotomy, and the underlying lung is normal or diseased. This can make a difference for how to determine whether there is a bacterial or other infection going on. Further, how often does the person take antibiotics? The potential for resistance is real but more likely when the person uses antibiotics frequently.

There are other strategies for preventing/controlling infections: daily hygiene, daily clearing of nasal passages with normal saline rinses, careful oral hygiene care, preventing reflux from the GI tract, limiting contact with infected people, vaccination for both patient and caretakers, adequate diet and hydration. Antibiotics ARE ONLY USEFUL FOR BACTERIAL INFECTIONS and might be needed when there are specific findings for infection such as a change in respiratory secretions to more in volume, viscosity, and color, and/or when coughing has changed to being more frequent and more intense. The only antibiotic which might be useful even in the absence of a specific BACTERIAL infection is Azithromycin, as it has an immune-boosting effect and has helped patients with interstitial pulmonary fibrosis, and it reduces the frequency of exacerbations for COPD. The patient may need to be examined by a health care professional to decide if an antibiotic might help.

**ANSWER:** *Linda Bieniek, CEAP (retired), IVUN Consumer Advisory Board Member, LaGrange, Illinois. Invasive vent user five-plus years; NIV prior 20-plus years.*

It is very important that the physician have a culture taken of the secretions/mucus to prescribe the right antibiotic for the type of infection the person has. The culture will show which antibiotics are effective/sensitive versus those that are resistant to this bacteria. Taking the wrong antibiotic is counterproductive and contributes to building resistance to these meds. Many doctors will prescribe the meds after talking with the patient over the phone. Mine did for years, and as a result of overtaking one antibiotic, I have developed a propensity to another infection. ▲



## Home Mechanical Ventilation Conference

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- guidelines for LTMV
- palliative use of NIV



Located on Spain's northern Mediterranean coast, Barcelona is a showcase for Gaudí's dazzling architecture.

Abstracts are due January 15, 2012.

Contact Brigitte Hautier, JIVD, +33 (0)4 78 39 08 43; [brigitte.hautier@free.fr](mailto:brigitte.hautier@free.fr); [www.jivd-france.com](http://www.jivd-france.com)

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