

The Fight for Home Care Ventilation in Brazil

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Until 2001, ventilation equipment in Brazil was provided only to those patients with chronic disorders who had the means to afford the home care structure, which is attached generally to private healthcare providers. Some of these patients remained hospitalized for a long time, often in ICUs.

For the majority of patients – mainly those with neuromuscular diseases – the ventilation option was not even offered. The reasons include unawareness of the symptoms of respiratory failure and the consideration by the doctors' teams that the treatment was not worthwhile according to the patients' conditions.

Also in 2001, the *Grupo de Pais* (Parents of Children with Muscular Dystrophy Group) was founded and started to fight to save that generation of children. Members of the group, including myself, got in touch with the government, traveling three

times to Brasília, the capital, visiting members of parliament and cabinets in charge of helping people with disabilities. The group finally had a hearing with José Serra, the Health Minister.

On September 4, 2001, our great victory came: the *Portaria 1531* (a directive law) that gives all muscular dystrophy patients the right to have respiratory assistance through bilevel noninvasive ventilation as soon as the clinical situation determines the necessity. Our patients have about half a dozen masks from which to choose, and these are replaced every six months. (Volume ventilators are not included in the *Portaria*.)

Unfortunately, the law was only on paper, and it was not being respected. We started to advise patients to petition to obtain bilevel ventilation. As directors of ABDIM (Brazilian Muscular Dystrophy Association), we were called by the Public Prosecutor's



Diego is not using oxygen but is undergoing capnography testing.

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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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IVUN and PHI announce the 10th International Conference, update the network on The Research Fund, and thank the sponsors of International Ventilator Users Network.

–Joan L. Headley, Executive Director

Office to give an explanation about why there were so many petitions. Touched by the situation, the prosecutor became an important ally and begged petitions against secretaries of state all over the country in order for them to also follow the *Portaria*.

The Health Secretariat of the State of São Paulo, where I live and which is the most developed and richest state in Brazil, called us and suggested we develop a state program for the distribution of bilevel ventilators. In that way, the structure of distribution of bilevel units was born.

The *Instituto do Sono* (Sleepiness Institution, www.sono.org.br) was and still is in charge of the program in the State of São Paulo, but only 80 out of 108 patients from ABDIM have ventilation under its responsibility.

It is extremely important that the support groups, friends, family members and patients themselves organize and act side by side with health professionals to insist that regional teams follow the guidelines of the respiratory and ventilation programs.

Besides São Paulo, only Minas Gerais, another Brazilian state, has a ventilator assistance program. Unfortunately, in other states there is the necessity of judicial measures to get the device and, even when it is granted, we bump into the ignorance of health professionals about specialized equipment, such as the CoughAssist®, needed to live at home with ventilation.

After *Portaria* was promulgated, we returned three more times to Brasília to talk to three different health

ministers, asking them to broaden the *Portaria* to cover all the neuro-muscular diseases and to include the CoughAssist® in ventilation centers throughout the country.

“It is extremely important that the support groups, friends, family members and patients themselves organize ...”

- Ana Lucia Langer, MD

Unfortunately, our requests have not been completely granted, but we are obstinate, and we will go there as many times as necessary.

In the State of São Paulo, the *Instituto do Sono* has already acquired some CoughAssist® devices, and the Health Secretariat has bought some units for ABDIM.

ABDIM lends patients the use of the CoughAssist® when they face respiratory infections and need help in expelling lung irritants. The mortality level of our patients has fallen to zero, during the last two years, after acquiring these devices. ▲

ABDIM

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Living with a Ventilator in Brazil

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Maria and Marcelo

I graduated in 1987 from Pontifícia Universidade Católica do Rio de Janeiro and began working as an electronic engineer at Centrais Eletricas Brasileiras – Eletrobrás (Brazilian Power System).

In 2000, I retired because my vital capacity had decreased greatly, due to respiratory complications while recovering from an emergency surgery to heal a bad abdominal infection and severe diverticulitis.

My retirement income is mainly what I live on because the government provides a very small financial aid to people with disabilities. I can say that I am really a lucky man, because I'm married to Maria de Fátima Lopes, a wonderful woman.

I received my first diagnosis of muscular dystrophy – Duchenne muscular dystrophy (DMD) – when I was about eight years old (1971). My parents began to notice some differences between my sister, who was a year older, and me. She ran faster, got up from the floor quicker, climbed stairs faster, jumped higher, and had more energy.

The DMD diagnosis was corrected some years later, because my progression was slower and didn't match that of Duchenne's. In fact I still don't have a definitive diagnosis, because my DNA test was inconclusive for DMD and a more detailed DNA test was too expensive for me. I probably have Becker's muscular dystrophy, although limb-girdle muscular dystrophy is another possibility, but with a lower probability.

I started using assisted ventilation in 1995, when I went into respiratory failure because of pneumonia and was trached. After recovering and letting the tracheostomy close, I began using a rented Respironics BiPAP® S/T during sleep.

The ventilator I use now is a Respironics BiPAP® AVAPS™, with an Advantage Series Silicone Nasal Mask that I like very much due to its durability and softness. This bilevel is quite small compared with the older BiPAP models, mainly because its power source is external, which keeps the BiPAP cooler.

My new BiPAP was supplied by the Brazilian Ministry of Health, after I won an eight-month lawsuit to force the Ministry to obey its own law about supplying a ventilator to all with muscular dystrophy who need assisted ventilation at home.

In Rio, the second richest state, an individual who goes to the Ministry of Health requesting a ventilator

with all the necessary documentation (including respiratory function tests and a doctor's order) is often told, "Unfortunately, there's no money to buy what you need." The only alternative is to sue the Ministry of Health, and sometimes (not often) cajole them into furnishing the equipment.

I know a situation where, after months of fighting, a boy received a nebulizer instead of a bilevel! One young woman with limb-girdle muscular dystrophy (www.acadim.com.br) has been waiting two years in a public hospital for the Ministry of Health to furnish the home care that a judge decided she should receive.

My physician, Ana Lucia Langer, MD, is Brazil's Muscular Dystrophy Association clinical director. She has fought hard for people like me to receive ventilators to be able to live at home. ▲

Pompe Disease Treatment

Pompe disease is a rare neuromuscular genetic disease in which certain enzymes are lacking. It can be treated with Myozyme®, an enzyme (αglucosidase alfa) replacement therapy from Genzyme Corporation that can be administered via a bi-weekly infusion. Individuals with Pompe disease relate their treatment outcomes below.

Maryze Schoneveld van der Linde

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I have received this treatment for some years now. When I began, my lung function capacity was 13%. As of July 2007, it is 20% capacity. I can't live without a ventilator, but now I can be without one for much longer. Last week I traveled to Budapest and I was able to go around with only an Ambu® resuscitation bag to ventilate myself intermittently. I have also regained my full energy. Lack of energy is a major problem with Pompe disease. With my increased energy and improved breathing ability, I am able to work fulltime and to travel again.

In my case, I don't think I will ever be able to be without a ventilator, but I do hope that others with Pompe disease who are able to start treatment in time (before the disease has impacted their diaphragmatic function) will not need a ventilator or a wheelchair. Even with a slight improvement in my situation, the impact of the treatment is huge.

Luke Garrett

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"IVs? A port in my arm? I have to do this?" My first reactions to the news of receiving Myozyme treatment were a little nerve-wracking. A frequent worry that controlled my mind before starting the drug was the unknown. "What was this drug going to do to me? Is it worth the possibility of a reaction to the medicine?" However, these worries faded as I became accustomed to the treatments.

Now, more than four years of treatments later, the abundant improvement continues every day. Playing baseball and going to school on a part-time basis are now activities that I can easily participate in. The improvements do not end there. My energy levels have also drastically increased, and I push to become even stronger with the help of Myozyme. But it hasn't been an easy road when physical therapy, exercises every day and diligence are required.

Days aren't all schoolwork and exercise. I spend time on my favorite hobbies, such as playing baseball, listening to music, and playing rock n' roll with my father and brother Max. If Max hadn't started to play the guitar four years ago, my inspiration to learn would have never sprouted. I owe it all to him.

My independent breathing is slowly becoming easier, although I still need the ventilator 24 hours a day. Without the help of Myozyme, my diaphragm may have gotten weaker, and improvement of its strength would have reached a plateau unfortunately.

I am grateful for the treatments that continue to be provided, and I hope to keep improving. ▲

Maryze is active in the International Pompe Association (www.worldpompe.org).



Luke Garrett, age 14

For more on Luke's story, go to www.ventusers.org/edu/valnews/val10-2b.html#liv and www.ventusers.org/edu/valnews/val17-1b.html#luk.

A Life Less Ordinary

Mark Siegel, Minneapolis, Minnesota, mcsiegel19@gmail.com

“The ventilator’s presence faded into the background clutter of my life as more of my attention shifted to school and other interests.”

I can state with confidence that if I had not started using a ventilator, I would not be writing this. Like many kids with SMA (spinal muscular atrophy), I was at the mercy of every virus or microbe that might decide to take up residence in my respiratory system. My parents made valiant efforts to keep me healthy, but I still managed to get several nasty colds each winter. Sometimes those colds would turn into pneumonia, followed by the inevitable hospital stay.

By my early teens, I had already made several trips to the University of Wisconsin Hospital in Madison, which was hundreds of miles from my home in Green Bay. My pediatrician began making pointed comments to me about a future life with a tracheostomy, but I didn’t want to hear it. I remembered the discomfort of a tube shoved down my throat, and the thought of having something like that as a permanent fixture of my body scared me.

It wasn’t long before I had to confront my fears. After yet another bout of pneumonia landed me in the hospital and on a ventilator, my doctors presented me with a stark choice. In order to go home without either a vent or a trach, I could spend the next several months in the hospital as I was slowly weaned from the vent or I could get a tracheostomy and go home with a portable vent.

My parents and I decided to go ahead with the tracheostomy. I was weak, and it would only be a matter of time before I would be back in the same situation. Better just to get it over with.

I won’t lie; the adjustment to life with a ventilator was far from easy. I deeply resented the loss of the little independence I had cultivated for myself before being admitted to the hospital. I had to get accustomed to the notion of having a nurse or family member with me at all times. My adolescent moodiness only amplified my anger. There was even some talk of placing me in a facility for kids

with intensive medical needs, but my parents quickly squashed that idea.

Little by little, things got better. My body (and the tubes coming out of it) didn’t feel quite as foreign to me as when I first came home from the hospital. The ventilator’s presence faded into the background clutter of my life as more of my attention shifted to school and other interests.

I had always had a fascination with computers, and a series of coincidences introduced me to assistive technology that allowed me to operate a computer with only slight head movements. Finding that device went a long way towards restoring my sense of independence.

I’m now on the verge of turning 35, and I’ve used a ventilator for more than two decades. In that time, I finished college and left Wisconsin to attend law school at the University of Minnesota. I became a licensed attorney and found work as a law clerk for a district court judge.

Siegel has used an LP10 for the last 10 years and before that the LP6. He gets around with an Invacare TDX3.

For the past six years, I've been employed at the Minnesota Department of Human Services where I work on policies to improve the lives of people with disabilities. I've done many of the things that most adults my age do: started a career, purchased a home in downtown Minneapolis, traveled to places around the country and points overseas such as Paris and Berlin.

In order to live independently, I depend on 24-hour private duty nursing funded by Minnesota's Medical Assistance program. After many years of using home care agencies and growing tired of their inability to retain good people, I discovered that I could hire nurses myself without using an agency.

Managing a staff of independent nurses has worked well for me, although it takes some effort to set up and maintain. It has also required me to become a more vigorous self-advocate. Nobody else knows my body and my needs as well as I do, and I've learned that I can't be shy about communicating that knowledge to my caregivers.

I still contend with the occasional frustrations that accompany life with a ventilator. My speech is sometimes slower than I'd like it to be. Privacy is scarce, and sometimes I can only find it in the glow of my computer screen. Ironically, I can also feel terribly alone on occasion.

And it's difficult to be spontaneous when I always have to consider things like battery charges and nursing shift changes. It's easy to become too focused on the daily minutiae of maintaining myself and my equipment. In the days leading up to my

trip to Europe, I remember being terrified that I would accidentally fry my ventilator by plugging it into the wrong outlet. But for the most part, things take care of themselves, and I don't give much thought to my ventilator use.

Despite the hassles and complications, I do not regret the decision to be trached and vented. I'm much healthier now than I ever was as a kid, and I don't get sick more than once or twice a year. My energy reserves are more than adequate to allow me to live a full life. With any luck, the ventilator will give me a few more decades to do the things I haven't gotten around to yet, like finishing that book and seeing a little more of the world.

I can't say that a trach/vent combo is right for everyone. It has worked well for me, but your circumstances and priorities may be different from mine. But I can say that life with a ventilator is not the bleak existence that many imagine.

In fact, I wish that my present self could somehow time travel back to 1987 to reassure my younger self that things would get better. That he can look forward to a future where he lives independently, has several close friends, and even the occasional girl takes a liking to him. I would tell him that it's a future worth living for. ▲



Mark Siegel

My Favorite Mask: FlexiFit™ 407

Gladys Swensrud, San Diego, California, swensrud@pacbell.net



Polio survivor Gladys Swensrud is co-facilitator of the San Diego Polio Survivors support group. She was instrumental in helping to create Kaiser/San Diego's Neuromuscular Respiratory Program, which is presently in the process of seeking expansion throughout Kaiser Permanente in Southern California. With her nasal mask, she uses a RedMed VPAP® III (ST) bilevel machine at settings of IPAP/12, EPAP/5 and a backup rate of 9 Breaths Per Minute (BPM).

Merriam-Webster defines a mask as “a cover or partial cover for the face used for disguise.” That definition instantly conjures up images of the Lone Ranger’s classic black mask. However, for those of us dependent upon bilevel or CPAP support, the function of our masks serve an equally noble purpose – aiding us in safe, restful sleep.

There are almost as many nasal and full face masks available today as there are sizes and shapes of faces. Finding the perfect mask to allow me to sleep in comfort throughout the night required a bit of experimentation. Fortunately, during that critical period I was under the care of the sleep professionals at Progressive Medical in Carlsbad, California. The therapist assigned to help me make this decision was Kelly. She fitted me for three or four different styles and brands. But as soon she hit upon one that matched my requirements, I was finally able to sleep peacefully, both through the night and when resting or sleeping during the day.

Each person’s comfort requirements are slightly different. I needed a mask that had a light touch against my forehead and sinus cavities. I wear glasses throughout the day, so I did not want to go through nights as well as days with pressure against those same facial areas.

After sleeping with the FlexiFit™ 407, manufactured by Fisher & Paykel Healthcare (www.fphcare.com), I concluded that their size small nasal mask worked best for me. There are multiple reasons for my success with this particular model:

- A foam cushion sets into the silicone seal to protect my face from undue pressure. It feels secure, yet comfortable, against my skin.
- The silicone seal pops off (and back on) easily for cleaning, so I am more apt to wash it daily, preventing skin irritation and skin oil buildup.
- A glider strap lets me turn my head while I sleep, but it keeps the mask stationary on my face.
- A well-designed air defuser vents air away from my body, so I am never bothered by air blowing down at my chest.
- Once it has been adjusted to my head size, the headgear generally only needs to be replaced once a year. I set it and basically forget it!
- The headgear disconnects from the mask for easy cleaning. I just put my headgear periodically in the washer on gentle cycle, and let it air dry afterward on top of the dryer.
- The headgear has a stretchy band at the rear for additional comfort at the back of my head.
- The easy slide hooks make it simple to disconnect and/or reconnect my headgear in the dark if I should need to get up in the middle of the night. ▲

Competitive Bidding: What It May Mean for You

In 2003, Congress passed the Medicare Modernization Act (the same bill that included Prescription Drug Coverage). Embedded in the bill was a provision called Competitive Bidding for Durable Medical Equipment, Prosthetics, Orthotics & Supplies (DMEPOS), such as wheelchairs, hospital beds, oxygen, walkers, and CPAP and bilevel units.

The purpose of the Act was to save Medicare dollars. In the case of DMEPOS, which accounts for only 2% of the entire Medicare budget, the savings goal is \$1 billion.

Ten large metropolitan statistical areas (MSAs) were chosen as competitive bidding areas for Round 1. Suppliers who do business in a competitive bidding area submitted bids to supply products and services. The lowest bidders were awarded a contract to sell to Medicare recipients. They are known as “contract suppliers” and cannot charge Medicare more than the single payment amount set by Medicare based on the bids received.

Non-contract suppliers can become “grandfathered” suppliers and continue to rent to their customers, if they accept the contracted payment, which is lower than their previous payment.

In fact, the average cut in reimbursement for CPAP and bilevel units is 26% and effectively removes the professional respiratory care component of treatment. The cuts seriously endanger the ability of the home health-care companies in delivering comprehensive and quality respiratory care to their clients. Home care companies need to do more than leave a bilevel unit, a mask and an instruction book on the doorstep, and should be compensated for the service.

Round 1 is scheduled to go into effect on July 1, 2008. Round 2 includes 70 more MSAs and goes into effect July 1, 2009.

There have been many procedural and operational flaws with the competitive bidding process, and the American Association for Homecare is lobbying Congress to delay implementation of Round 1 until these problems can be addressed and corrected. For more information, go to www.aahomecare.org and www.cms.hhs.gov/CompetitiveAcqforDMEPOS.

Write your Congressperson today to urge him or her to sign H.R. 2231, Medicare Access to Complex Rehabilitation and Assistive Technology Act of 2007. This bill exempts complex rehabilitation products and assistive technology products from competitive bidding. (<http://thomas.loc.gov>) ▲

Pompe Disease Treatment

The enzyme-replacement treatment for Pompe disease is available in the U.S. and Europe. Currently, Trevor, a 17-year-old Canadian with Pompe disease, is trying to convince the Canadian government to reimburse for this treatment.

To sign an online petition to support Trevor and other Canadians with Pompe disease:
<http://petitions.takingitglobal.org/TrevorPare>

See page 5 for update on Pompe Disease Treatment.

From Around the Network

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

New Products



LTV® 1150 on back of wheelchair in Transport Pack.

Mirage® Micro™ is a new nasal mask from ResMed Corp. It has a MicroFit dial and dual-wall cushion to achieve a good and comfortable fit. The forehead support allows for a streamlined field of vision.

www.resmed.com



ComfortGel™ Full Face Mask from Respirationics features a newly designed forehead cushion with adjustment by StabilitySelector®. The blue gel cushion is removable and easy to clean, and combined with the sure seal technology (SST™) flap, provides a comfortable fit.

www.respirationics.com



LTV® 1150 from Cardinal Health's Pulmonetic Systems Division is the newest in the LTV series. It enables patients who are using the LTV® 1200 in the hospital to go home with the LTV® 1150. The main advantage is the ease of transition from hospital to home and internal (instead of external) PEEP. www.pulmonetic.com

Dealing with Bacterial Infections

Ines Gaudet, Rochester, Minnesota, inesita56@earthlink.net

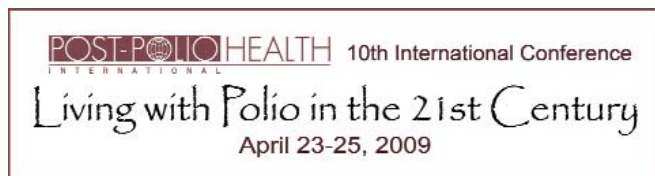
I developed respiratory problems and spent some time in the hospital in December with infections from both *Pseudomonas aeruginosa* and *Staphylococcus aureus*. It's been a long-standing problem for me since I started using trach positive pressure ventilation in 1980. This time I received two weeks' worth of antibiotics through a PIC line: vancomycin for a week and meropenem for two weeks. It took me quite some time to recover and get my strength back.

On my last bout with *P. aeruginosa*, meropenem cleared up things completely. Not so this time (I still get green secretions), but I am asymptomatic at the moment and feeling well. The question becomes at what point do we use prophylactic treatment before things get out of hand? I no longer respond to tobramycin by nebulizer. I am particularly thankful that I did not have methicillin-resistant *Staphylococcus aureus* (MRSA).

I have often wondered how other people with *P. aeruginosa* keep it under control, although I'm amazed by the differences in techniques and practices in trach care among ventilator users. I use sterile techniques to suction, and I change my trach twice weekly. I use disposable tubing with both of my ventilators for one week. There are a few pieces of equipment that are cleaned with Control III disinfectant. (Some people swear by vinegar as a disinfectant.)

I have been trying antimicrobial tracheostomy dressings and think that they have a good effect on my stoma. I even tried the sanitizing cycle on the dishwasher for some of my equipment, but not all of it is able to withstand the high temperatures. Even among respiratory therapists, I have seen and heard differences of opinion about all of these issues. It would be helpful to have guidelines. I'd like to hear from others about their methods of dealing with bacterial infections. ▲

Mark your calendars!



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Warm Springs, Georgia, is located 70 miles southwest of Atlanta.

As in prior years, the program will include sessions specifically aimed at users of home mechanical ventilation.

Watch www.ventusers.org and www.post-polio.org for details.



The 12th International Conference on Home Mechanical Ventilation will take place in Barcelona, Spain, on March 27-

28, 2009. The conference organizers invite physicians, paramedics, technicians, therapists, home care providers, psychologists, administrators and ventilator users to participate. The deadline for poster presentations is December 31, 2008. For details, contact brigitte.hautier@free.fr.

Research

IVUN and PHI's Research Fund

"Regulatory T Cells as a Biomarker of Post-Polio Syndrome"

The final report from the team at the University of Arkansas for Medical Sciences (UAMS), recipient of the fourth grant award, was published in *Post-Polio Health* (Volume 24, Number 2). Contact info@ventusers.org to receive a print copy.

The Review Panel is in the process of reviewing the eight proposals submitted for the fifth award of \$25,000 to be given in 2009. The grantee will be announced in late 2008. ▲

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