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SHERRY HURST:

"I Plan to Celebrate My 100th Birthday!"

Sherry Hurst, Lubbock, Texas

Okay. Here's what I've come to realize about everything that has happened regarding my health since late last year. I went to see a pulmonologist about what I could do in order to be able to travel.



I was having to spend 16 to 18 hours a day in the "tank" (my iron lung), and I could manage about 5 to 6 hours in my wheelchair. I try to stay as active as possible in advocacy for elder, education, homeless and, of course, disability issues.

[Sherry contracted bulbar polio in 1955 at age 3. See sidebar story, below.]

Of course, the immediate question about trach and ventilator came up – to which I said a resounding and emphatic, "NO WAY!" When asked, "Why not?" I gave some lame excuse about pseudomonas – the reliable and unarguable comeback. [Pseudomonas is a bacteria that can cause severe infection including pneumonia.]

However, the truth is something quite different.

You see, growing up, "trach" was something that only entered last-minute, last-ditch efforts as a "lifesaving Hail Mary" in the medical sense. At least that's the message I picked up as a kid and carried with me into and throughout my adult years.

Trach also carried the connotation of "failure" with it. I'm not sure failure at or about what. It really didn't matter. What did matter, above all else, was not failing! I'm sure there are some other driven polio survivors out there nodding and smiling just a bit.

On December 18, I got very ill and ended up in the intensive care unit intubated with kidney stones in both kidneys requiring a surgical procedure. Next, I developed double pneumonia severely damaging both lungs and requiring full-time ventilator support. I, of course, fought stubbornly to get myself to where I could come home and get back to my beloved tank, convinced everything would be okay.

About Sherry

Sherry contracted polio in 1955 when she was three years old in Abilene, Texas. A year later, she was transferred to the Gonzales Warm Springs, a rehabilitation hospital, where she spent the next two years "being stretched, fitted for equipment and taught how to function with all the new contraptions used for coloring, eating, etc."

She had used an iron lung for two months, was gradually weaned to a rocking bed and then a regular bed with no breathing assistance. However at Gonzales, she developed pneumonia and was placed back in the iron lung. Unable to handle respiratory cases, Gonzales transferred her to Houston to what became TIRR Memorial Hermann Rehabilitation Hospital.

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Hamilton Medical Receives FDA Clearance for MR1 MRI-conditional Ventilator

Hamilton Medical has announced that its **Hamilton-MR1 ventilator** has received FDA clearance for use in a hospital or MRI (magnetic resonance imaging) facility. Transporting patients who use ventilators and maintaining ventilation during the MRI can be a challenge for medical professionals.

Hamilton's MR1 covers a range of clinical requirements – invasive ventilation, automated ventilation with Adaptive Support Ventilation and noninvasive ventilation. It is not available for use within the home care setting.

With the effectively shielded MR1 ventilator, the MRI environment's strong magnetic fields do not interfere with ventilation performance or the MR image quality. It is programmed to alarm if the clinician places it too close to the MRI magnet. The MR1 offers flexible noninvasive positive pressure ventilation and full-featured ventilation for both adult and pediatric patients. The MR1 delivers small tidal volumes with the highest degree of accuracy and guarantees a perfect synchronization with every patient.



Positioning a medical device too close to the MRI can have fatal consequences and cause serious injury to the patient or clinician, and significant financial losses can occur if an MRI shutdown is required. The Hamilton-MR1 continuously monitors the magnetic field and gives the clinician both an audible and a visual signal if it is getting too close to the MRI magnet. Because close proximity

of the ventilator to the MRI machine is crucial, the MR1 can be used at a magnetic field strength of 500 gauss without creating any MR image artifacts.

The MR1 includes a trolley made of non-ferrous materials that will not be attracted to the powerful electromagnetic forces emanating from the MRI's magnet. The trolley also has a "fail-safe" braking system. ■

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

Hospitals Testing New Procedures for Lung Disease without Major Surgery

The *Wall Street Journal* reported April 14, that more than two dozen U.S. medical centers are testing a less-invasive new procedure to help patients with lung disease.

Some 15 million Americans have been diagnosed with COPD (short for Chronic Obstructive Pulmonary Disease), a lung disease caused mainly by smoking that includes chronic bronchitis and emphysema. Over time, this disease makes it hard to breathe. Currently, it is the third leading cause of death in the United States behind heart disease and cancer.

The *Journal* article says that some patients with severe cases of COPD may undergo surgery, during which the diseased part of the lung is removed, but that this procedure is risky and costly partly because recovery is long and many patients experience complications after surgery.

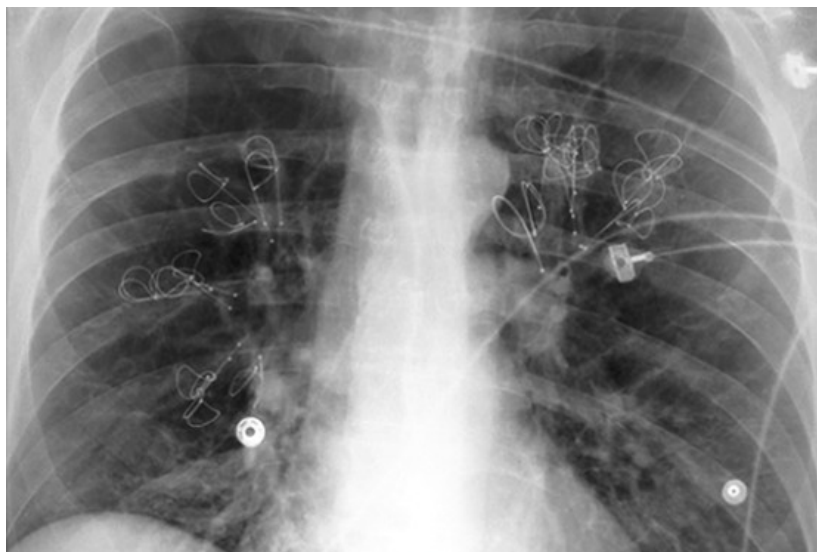
According to the *Journal* story by Laura Landro hospitals are “testing a technique that places metal coils into the lung using special scopes inserted through the mouth or nose. Once in place, the coils compress the diseased tissue and allow the healthier parts of the lung to breathe more freely.”

The report cites Atul C. Mehta, an interventional pulmonologist at Cleveland Clinic, one of the centers participating in the trial: “If successful, we will be able to help a significant number of patients have an improved quality of life and potentially improve survival in a noninvasive manner.”

The story notes that the coils have been approved for use in Europe since 2008, and studies have shown the treatment is safe for patients, resulting in significant improvements in pulmonary function, exercise capacity and quality of life. PneumRx Inc., the manufacturer of the coils is funding the U.S. research.

According to the PneumRx website (www.pneumrx.com), the coils are programmed with shape memory, meaning that after being straightened for insertion into the lung, they gather up and compress the diseased lung tissue surrounding them as they return to their original shape, improving lung function in three ways:

- ♦ The coils compress diseased tissue, which provides room for healthier tissue to function;
- ♦ The coils retention adjacent parenchyma, helping to restore the lung’s natural elasticity, which enables the lung to more efficiently contract during the breathing cycle;
- ♦ The coils tether open small airways, preventing airway collapse during exhalation, which reduces air trapping and hyperinflation. ■



X-ray showing a patient’s lungs after coil treatment.

Photo credit: Dr. Gerard Criner, Temple University

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By mid-January, I was moved to a specialty hospital to continue my stubborn attempts, but after two or three weeks and no improvement, I was forced to choose: God-awful permanent oral intubation living in a skilled nursing facility, a nice euphemism for a nursing home/warehouse OR go ahead with trach and vent, return home with Medicare



providing ventilator, monthly supplies, respiratory therapist, hospital bed with alternating pressure mattress to prevent bedsores and other supports as needed. These combined with the Medicaid Waiver program I'm on that provides attendant care made the choice fairly obvious.

So on February 1, I got my tracheostomy, and my life changed forever.

However, much to my surprise, the change has been a blessing! I'm actually quite amazed at how easily I've made the switch to trach and full-time vent (Philips Respironics Trilogy100). It has given my attendant and me the freedom and ability to travel, something we really couldn't do before. I was able to replace my old 1994 van with an almost-new fully accessible van, and I replaced my 24-year old wheelchair with a snazzy new model.

The thing my attendant and I miss is the ability to hear my voice whenever I speak without having to deflate the trach cuff and then inserting the speaking valve, which I really don't need because can be

About Sherry

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"My parents realized early on that my mind was going to be my most valuable asset in life." She started first grade via an intercom system set up by the phone company. "I began my academic career in a one-room schoolhouse – our kitchen," she said.

Starting the third grade in Austin, where her father had been transferred for work, she entered a pilot program for elementary students with various physical disabilities. "This was great," she recalled. "I could go to school, be with other kids and still have physical therapy and a rest in the afternoon."

By fourth grade, she was able to "mainstream" in some classes, and then her father was transferred to Texas City, where there were no special programs. "We worked out a deal with the schools that I could attend regular classes with no special considerations as long as my presence wasn't disruptive. I did wonderfully. I came home exhausted the first couple of weeks, but mainstream class education was the best thing that ever happened to me."



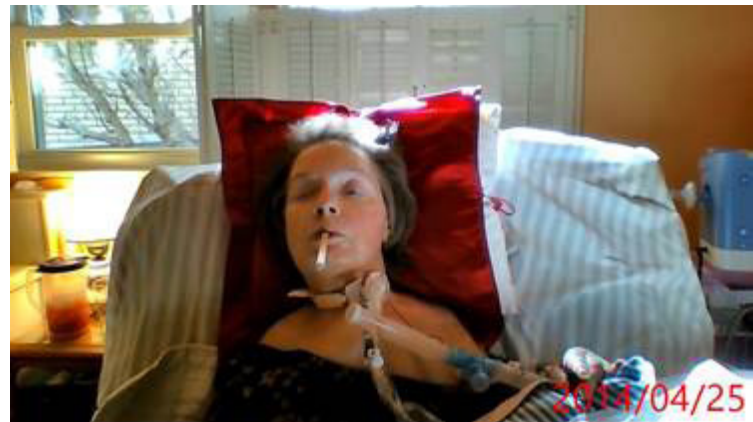
Sherry in her "tank."

heard perfectly fine by just deflating the cuff and allowing air to flow over my vocal cords. Either way, I can talk for about 20 to 30 minutes before having to stop for suctioning.

Trying to put into words how something Satan was trying to use to defeat me and make me question my faith is very difficult. I do know that God turned this around and provided not only for my

needs (better ventilation and health), but he also gave me my wants at the same time. Now I can travel, enjoy my new wheelchair for more than four to six hours a day, and, of course, our new car.

So, God is in control and life is fantastic! I have a lot of living to do. I told y'all I plan to celebrate my 100th birthday! ■



Sherry's attendant since 1998, Nicky Sachchabutra (right), with Sherry's late mother.

In addition to the stimulation of healthy competition and socialization, "I learned that I could get along in a world structured for the able-bodied and be successful." From then on, Sherry attended public schools in Texas and New Mexico. During this time, both Sherry's parents worked and she had a number of attendants, some of whom doubled as housekeepers. When she was a junior in high school a young woman who was starting business school was employed as an attendant in exchange for room and board.

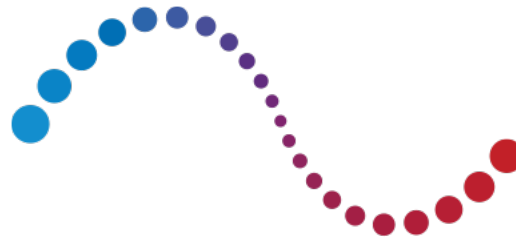
She and Sherry became fast friends, and in 1970, both entered Texas Tech University as freshmen. "We were instrumental in the ramping of much of the campus." Sherry earned a bachelor's degree in psychology in four years and returned as a graduate student to earn a teaching certificate in secondary education and later, as a master's candidate in English.

Sherry has been a volunteer in the Lubbock School District and chairman of the volunteer program for eight elementary schools. She was nominated by the Lubbock School District as volunteer of the year and was one of 12 semi-finalists nationwide. ■

ResMed Unveils a New Brand

“Changing lives with every breath” is the new tagline for a refreshed ResMed brand that the company says aligns ResMed’s appearance in the marketplace with its global focus on innovation that benefits patients’ lives.

ResMed’s new logo includes an updated wordmark combined with a visually appealing “pulse” curve that shifts in color from bright blue to rich red, symbolizing the transition that deoxygenated blood makes to oxygenated blood with every breath and every beat of the heart.



ResMed
*Changing lives
with every breath*

“Our new brand speaks clearly to our partners – from physicians to home care providers to patients – that ResMed is the industry leader because we are steadfastly focused on changing lives with every breath,” said CEO Mick Farrell.

The new brand transition starts with ResMed’s U.S. operations and will roll out globally throughout the year. A key element will be an updated and user-friendly company

website – www.ResMed.com. ■

About obsolete equipment

Sherry Hurst would like to donate her functioning iron lung with a rebuilt motor and gear box and other various accessories to an individual or organization. If you or someone you know is interested, please contact info@ventusers.org. Transportation from her home to another destination is not included.

How many iron lungs are still in use? In addition to the number, the history of ownership and maintenance of the iron lung used by the majority of polio survivors in the United States is complex and was recorded using the Post-Polio Health International archives by Joan L. Headley. *The Iconic Iron Lung and Polio Survivors in the USA* was published in *Post-Polio Health* (ISSN 1066-5331), Vol. 30, No. 1, Winter 2014. It can be read online at www.post-polio.org/edu/pphnews/PPH30-1win14p3-5.pdf.

Service discontinued as of December 31, 2014. In a November 2009 letter Philips Respironics notified customers of the PLV-100, 102b and 102 that they would no longer be manufactured after December 31, 2009. The letter further stated that “all reasonable efforts would be made to provide rental units, service replacement parts and technical support to our customers through 12/31/2014.” IVUN coordinated a series of conference calls in 2012-13 for ventilator users who use these devices. The presentations and summaries of the calls are available on IVUN’s website at www.ventusers.org/edu/confcalls.html#pas.

Pneumobelt bladders (medium) and an NEV-100 have recently been requested by polio survivors who use them and are in need of back-up. Contact info@ventusers.org if you have either to donate. ■

Letter to the Editor

Dear Editor:

I just finished reading the latest issue of *Ventilator Assisted Living*. As I read the two articles, “World Health Organization Releases International Perspectives on Spinal Cord Injury” and “Ventilator-Assisted Individuals; Integrating Across the Spectrum of Care,” I am reinforced in my belief that I have been doubly blessed. I have been blessed because I am a survivor of polio. I have also been blessed because I reside in, and am supported by, social and medical communities that understand ventilator use.

When I faced declining pulmonary capacity, and had to make critical choices, I had many examples of long-term ventilator users as friends. We had known each other for many years, some of them since the polio epidemics of the 1950s. I knew they were able to function well using a variety of home mechanical ventilation options.

And, as I faced these choices, I was surrounded by medical personnel who understood home mechanical ventilation. Each of these medical professionals had worked with hundreds of home mechanical ventilation users.

I'll add another blessing. The blessing of having very supportive family and friends, and living in a state (California) that has a good home care program.

Richard Daggett



Camper Jessica Leyva from Central Florida at a sailing event during Miami Children's Hospital's Ventilator-Assisted Children's Center Camp 2014, on a boat with Harry Horgan, CEO and President of Shake a Leg at Biscayne Bay.

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Sherry Hurst:

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