

The Iconic Iron Lung and Polio Survivors in the USA

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PHI is frequently asked how many iron lungs are still in use. Respironics Colorado reports renting iron lungs to three individuals and providing parts and service to four other patients who own their device. All of these iron lungs were made by the J.H. Emerson Company, Cambridge, Massachusetts. However, the history of ownership and maintenance of the iron lung used by the majority of polio survivors in the United States is complex and warrants recording, using the PHI archives.

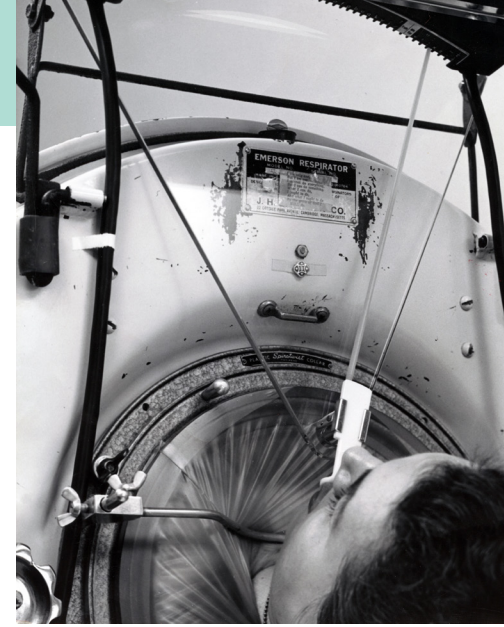


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Point of reference: A brochure revised in June 1946 (seventh printing) entitled *Respirators: Locations and Owners* was published by The National Foundation for Infantile Paralysis (NFIP). Basil O'Connor, president of NFIP, explains in the introduction that it is a list of the adult cabinet type respirators or “iron lungs.” The list totals 1,211 in the contiguous 48 states plus Washington, DC, and Hawaii. Owners included hospitals, the U.S. Army, fire departments, chapters of the NFIP, American Legion and other service groups, county medical societies and individual physicians and local citizens.

A timeline can more easily tell the rest of the story.

1968

James C. Campbell, a graduate of the University of Colorado, worked for the IBM Data Processing Division for 11 years before he started LIFECARE International, Inc. He was the Chairman and CEO of the private company from April 1968 to October 1996. The company designed, manufactured, distributed and serviced the successful PLV-100 (1984) and PLV-102 (1985) volume ventilators, among other devices.

1969

LIFECARE became a dealer of products for the Puritan-Bennett, Emerson, Monaghan and Thompson Respiration companies. The company then entered into a contract with the March of Dimes to maintain, for a monthly fee, respiratory

equipment provided by the March of Dimes to the surviving polio population. The respiratory equipment (e.g., the Monaghan 170-C, Thompson Bantam and Maxivent, Huxley, etc.) was scattered around the country in “equipment rental pools.”

Survivors received letters telling them of the switch from working directly with the March of Dimes to LIFECARE. A March 5, 1969, letter from the Metropolitan Chicago Chapter of the March of Dimes says, “As you undoubtedly know, public support of the March of Dimes has markedly decreased since the success of the Salk and Sabin vaccines.” It further explains that “... it is necessary to consider other available resources” and suggests “... it is possible that you may qualify for assistance with this expense though the Medical Assistance Program, which is financed jointly by the State of Illinois and the Federal Government.”

Some survivors thought that the equipment they received from the March of Dimes was “their property,” and they were surprised when another entity became involved.

1970

J.H. Emerson stopped manufacturing their model of iron lung. The prototype was made in 1931. The exact number manufactured is not readily known but thousands were manufactured, “with limited production during the 1960s,” according to a May 2004 company letter.

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1976

LIFECARE worked with Medicare and Medicaid to provide ventilators at home as a reimbursed benefit and helped establish the home ventilator industry.

1983

LIFECARE converted the last March of Dimes equipment rental pool center in Augusta, Georgia, to a LIFECARE District Office, one of 18 offices.

1984

LIFECARE International, Inc. purchased the March of Dimes equipment in the rental pools that it had been maintaining. Before the sale, March of Dimes notified those on the program in a March letter that it would be the payer of last resort. The rental and maintenance fee paid to LIFECARE was first by Medicare, Medicaid or private insurance. March of Dimes continued to pay for those without any other method of support. Some survivors never revealed that they had other means of support, adamant that the March of Dimes should pay. It did.

1987

March of Dimes and LIFECARE agreed to add the PVV (portable volume ventilator) to the program.

1988

LIFECARE established its Shared Services program, now part of Respironics Colorado, to assist dealers in providing ventilators to users. This included the polio survivors who received their first equipment from the March of Dimes.

1991

The number of polio survivors in the LIFECARE/March of Dimes collaboration was 348, of which 35-38% depended completely on the March of Dimes.

1993

Because its contract with LIFECARE would expire in March of 1994, March of Dimes evaluated its situation and decided that it would no longer accept new polio survivors to the program as of January 1. They stated in January 25, 1993 memo, "Patients currently receiving financial

assistance will be requested to complete a financial assistance questionnaire, which will be evaluated based upon need. Current patients meeting the criteria will be grandfathered." The letter provided a referral list of other groups to ask for assistance.

They further explain that their mission for the last 35 years has been to prevent birth defects and infant mortality and "forms the basis for its appeal for support from the public." Some polio survivors receiving the letters were concerned that private insurance, Medicare or Medicaid would not help pay for their home respiratory equipment. They did in most cases. The March of Dimes continued to cover 100% of the expenses for those unable to obtain other financial assistance.

1996

Respironics purchased LIFECARE International, Inc. In the late '90s, March of Dimes and Respironics agreed to add the PLV-100 to the program.

2004

Parts to service the J.H. Emerson iron lung were harder and harder to find. Respironics notified all of the individuals (and their physicians) who were renting an iron lung from them of the situation. The company offered three options in a May 10, 2004, statement:

"Transition to an alternative device as soon as feasible;
Continue using the Iron Lung Device with the understanding that if the device fails Respironics Colorado may not be able to repair the device;

or,

Accept donation of the device and pursue other support and repair options. As a company regulated by the Food and Drug Administration and other quality system certification organizations, we have limitations on the suppliers and repair sources we can qualify and accept into our quality system. However, the owner of the device, in this case the patient, may seek such repairs from a non-regulated third party."



Photo credit: PHI Archives



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Again, polio survivors who used the iron lung and their families were concerned and frustrated. Opinions ranged from “it is understandable that repairing a device made that long ago would be difficult” to “a multi-million dollar company should be able to just make the parts.” Through the next months, survivors and their physicians worked with the company to resolve the issue the best they could for each situation.

A few iron lung users switched to positive pressure ventilation via a nasal or face mask. Some switched to the Porta-Lung, developed by polio survivor W.W. “Sunny” Weingarten and made available in 1988. Weingarten designed the smaller, lighter-weight device so he could travel extensively. The Porta-Lung was distributed by LIFECARE.

How many chose which option is proprietary knowledge, but PHI assisted in locating iron lungs that had been purchased and were in storage and no longer in use, so a working back-up could be stored near each iron lung user or warehoused (in Houston) for parts.

Unfortunately, a rumor started that Respironics was gathering iron lungs to destroy them or sell them to Third World countries, so they wouldn’t have to maintain them. Consequently, a few iron lungs were not made available to the Respironics technicians.

2008

Respironics was purchased by Philips Healthcare. In January, they ceased the distribution of the Porta-Lung, which is powered by a negative pressure

ventilator, e.g., the NEV-100, a Respironics product. The company sent letters of notification to all of its clients and durable medical equipment companies about the stoppage of their distribution of the Porta-Lung, adding that it could be purchased directly from Porta-Lung, Inc. The memo continues, “Depending on customer demand, inventory levels and parts accessibility, Respironics will continue to provide support for both the NEV-100 and the Porta-Lung through December 31, 2010.”

2014

Fortunately, to PHI’s knowledge, every individual to this day has had their iron lung serviced. This includes those who accepted the iron lung as a gift with the idea they would assume responsibility for repair.

Unfortunately, individuals who use the NEV-100 to power the Porta-Lung (the device they switched to when the iron lung was “iffy”) are searching for a replacement for the NEV-100 and the Porta-Lung. Respironics Colorado is reasonably sure that they have stockpiled parts to meet the needs of their NEV-100 and Porta-Lung customers.

As an addendum, the Respironics Colorado clients who use the PLV-100 and PLV-102, were notified in November 2009 that these ventilators would no longer be serviced after December 31, 2014.

PHI’s affiliate International Ventilator Users Network (IVUN) organized a series of conference calls, funded by the March of Dimes, in late 2012 and in 2013 explaining the options that individuals should explore to find replacement equipment. The PowerPoint slides and summaries of these calls are available at www.ventusers.org/edu/confcalls.html#pas. ■

Are there more iron lungs in the USA?

To PHI, the number that is the most important is the number of people who use them. Next in importance is the ability to maintain them for their lifetime.

What is the total number of iron lungs in the USA today? No one knows for certain, although someone on Wikipedia asserts that there are 19 in Houston, Texas. That number cannot be confirmed by post-polio experts in Houston. One could speculate that this is the number rumored to be in the warehouse collected for back-ups and spare parts.

Some are in museums. Some may still be in hospital basements. Some may be in homes, still in use and not part of the March of Dimes/LIFECARE/Respironics story told here.

If you personally know of an iron lung in the United States, let PHI know so that it can be recorded on PHI’s website. Reporters, who often ask that question, will be glad to know the answer.