

IVUN. NEWS

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and July.

International Ventilator Users Network (IVUN) links ventilator users with each other and with health care professionals interested in home mechanical ventilation.

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IVUN MEMBERSHIP:
\$5 for ventilator
users.
\$15 for health
professionals.

Welcome to IVUN!

The International Ventilator Users Network (IVUN) is a worldwide network of ventilator users and health care professionals experienced in home mechanical ventilation.

IVUN officially began in 1986, but the network has been in existence among the readership of the Rehabilitation Gazette (formerly Toomey j Gazette) since the polio epidemics of the 1950s. IVUN evolved to meet the new respiratory needs of polio survivors and to share their experiences with long-term ventilator use with others.

Rehabilitation Gazette, an international journal of independent living by people with disabilities, was started by Gini Laurie in 1958 for polio survivors in iron lungs to share their information and experiences. The Gazette's early pages are full of creative adaptations and techniques for using a vent-a ventilator and living independently at home while working, attending college, travelling, raising a family, etc. The Gazette enlarged and expanded to include other physical disabilities and the aging of all persons with disabilities.

Polio survivors form the nucleus of IVUN since they spurred developments of equipment such as the iron lung and positive pressure ventilation. Their experiences with home ventilation are invaluable for persons with high level spinal cord injuries, muscular dystrophy, ALS, and other neuromuscular diseases, and for the new population of technology assisted infants and children.

Future issues of IVUN News will feature glossopharyngeal breathing techniques, long-term home ventilator use, sleep disordered breathing, travel with ventilators, creative adaptations for ventilators, psychological adjustment to ventilators, attendant care, legislation, and funding sources.

VENTILATOR ASSISTED HOME CARE PROGRAM

Kathryn Kirkhart, PhD, Coordinator, Children's Hospital, New Orleans, Louisiana

Children's Hospital in New Orleans is now in its fourth year of a program funded by Maternal and Child Health for home care systems (model) development, advocacy, training, and services expansion.

Currently, 43 families have participated in the program. The program is expanding to provide direct services to ventilator users and their care providers in Louisiana, including case management and training services. Funding was secured with legislative approval through Louisiana Medicaid, a new (optional) service to the state's Medicaid program.

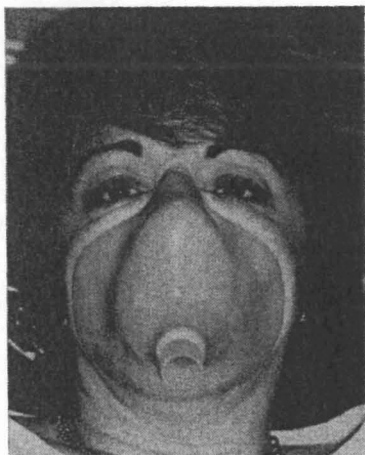
Coordinated by Kathryn Kirkhart, PhD, and directed by A. Joanne Gates, MD, the program has published a 77-page book, Homeward Bound: Resources for Living at Home with a Chronically Ill Child (available for \$4.00).

An hour long videotape orientation and training presentation for respiratory care at home will be available in the spring of 1987 with a companion training manual. Both cover philosophy and techniques of home care management.

Address: Kathryn Kirkhart, PhD, Children's Hospital, 200 Henry Clay Ave., New Orleans, LA 70118. 504/899-9511.

CUSTOMIZED FACE MASK FOR NIGHT VENTILATION

Susan Sortor, RRT, Director, Cardiopulmonary Services, Dallas Rehabilitation Institute (DRI), Dallas, Texas



Customized face mask

A unique night ventilation system for persons with respiratory muscle paralysis or fatigue has been implemented through the efforts of DRI's Susan Sortor and a Dallas oral prosthodontist, Dr. Carolyn Parker.

The system incorporates a customized mask which provides appropriate candidates with an alternative to tracheostomy tubes, iron lung, pulmowrap or other bulkier ventilation systems.

The idea originated when Sortor met Brunhilde Bung of West Germany during the 1985 GINI polio and independent living conference in St. Louis.

A dentist in West Germany made an acrylic mask perfectly molded to Bung's face. Bung uses the mask at night for ventilation.

Sortor first tried the idea with a 22-year-old outpatient named Maureen who had a paralyzed diaphragm and was experiencing respiratory fatigue at night. Maureen had not been content with the more traditional ventilator options and was excited to try the mask.

The first mask took about two weeks to make. It was made of acrylic with upper and lower bitewings inside the mask to separate the teeth into a relaxed position and hold the mask in place on the face. It used positive pressure ventilation

so it was critical that the fit be exact and no leakage occur. It required two nights of careful monitoring during sleep and adjustments throughout the night before a perfect and comfortable fit was achieved.

The success with Maureen's mask encouraged Sortor to offer the mask to other ventilator users. Sortor next fitted an inpatient with a C3 spinal cord injury. She has also explored the mask with post-polio outpatients who have respiratory fatigue at night.

Although the mask is time-consuming to make and fit, it does have advantages. The bitewings inside the mask reduce the tendency for dental complications, because they hold the teeth in a more relaxed position and use the entire biting surface to hold the mask in place. By enabling persons to breathe through the nose, the mask also enables the body's own filtering systems to operate, and thus reduce the risk of infection.

Address: Susan Sortor, RRT, Dallas Rehabilitation Institute (DRI), 9713 Harry Hines Blvd., Dallas, TX 75220. 214/358-8341.

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ED NOTE: Related articles in Rehabilitation Gazette:

"Lipseal and Diving Mouthpiece" by Oscar Schwartz, MD, Volume 26, 1985, page 64.

"Go Positive with Face Mask and Mouthpiece" by Adolf Ratzka, PhD, Volume 25, 1982, pages 65-67.

"Mouth IPPV for Sleep" by Augusta Alba, MD, Volume 24, 1981, pages 47-49.

MOBILE VENTILATOR UNIT

Leah Welch, Minneapolis, Minnesota

Respiratory polio survivor since 1949, Welch is director of an independent living center.



Leah Welch

Leah Welch, ventilator user, has designed and manufactured a unit which mounts a battery operated positive pressure ventilator with a battery operated humidification system for the ventilator on Welch's wheelchair.

The battery and the generator which operate the humidifier are mounted on a trailer which attaches to the rear of the wheelchair with a trailer hitch. A tray mounted above the generator and battery holds a portable suction machine.

The battery is a Trojan marine deep cycle acid battery, and the generator is a 500 watt Redi-Line electric generator with enough power for up to four or five hours.

Although cumbersome, Welch's trailer provides her with freedom and independence to travel with all the respiratory equipment she needs. Welch is director of Independence Crossroads, an independent living center in Minneapolis.

Address: Leah Welch, Independence Crossroads, 4240 Fourth Avenue South, Room 422, Minneapolis, MN 55409. 612/822-5655.

A CHAIR THAT GOES SAILING

by Basil Chenevert, Lincoln Park, Michigan

A retired Ford Motor Co. mechanical engineer, Chenevert was diagnosed with ALS (Lou Gehrig's disease) in 1979.

After looking through many catalogs and failing to find a chair with all the features I thought were necessary, it seemed apparent that the only way I could get what I wanted was to design and build my own.

In addition to comfort and mobility, design requirements included features to permit easy insertion and removal of a hydraulic transfer lift sling; to convert to a cot for afternoon naps; to facilitate hair washing; to transport as litter or car seat; and, for my own particular passion, features that would permit me to sail once more aboard our 28-foot sailboat, "The Second Wind."

To shortcut the process and take advantage of lightness and relative strength, my two sons and I used a conventional beach chaise lounge to support my foam rubber seat and back cushions. We removed the footrest frame and, after stripping it free of its plastic covering, attached it to act as a hinged back support. (See diagram on opposite page.)

By disabling the ratchets, the position of the back can be set in an upright position for transportation, in a semi-reclined position for comfortable daytime seating, and a fully reclined position. This metal frame is mounted on a separate wooden chassis which has a pair of 8" wheels under the rear chair leg. The wooden frame is held at a comfortable seating angle by a pair of fixed front legs. The front extension holds the footrest and a handle that can be used to move the chair wheelbarrow fashion.

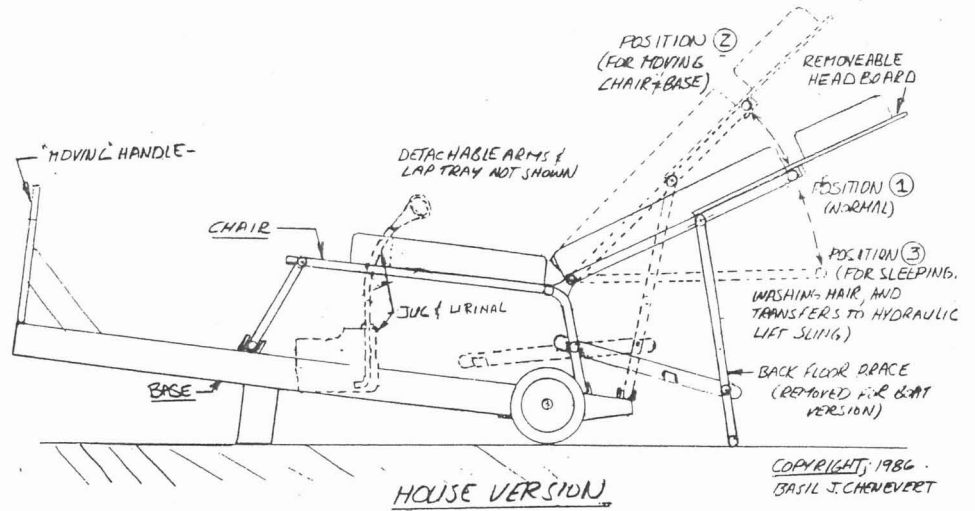
Individually removable arms are cleated to the wooden frame, and a separately removable lap tray, complete with a privacy skirt, rests on the end of the arms. The seat cushion houses a urinal, and the chair frame supports a reservoir jug so that it goes with me when I am moved.

A separate headboard and pillow arrangement can be removed, and my head can be supported above a portable wash basin for hair washing, with the chair in a reclined position. In this same position, with the headboard in place, and with the arms and the tray removed, the chair can be used as a cot for napping. It provides easy access for rolling me from side to side for insertion or removal of the hydraulic lift cloth sling.

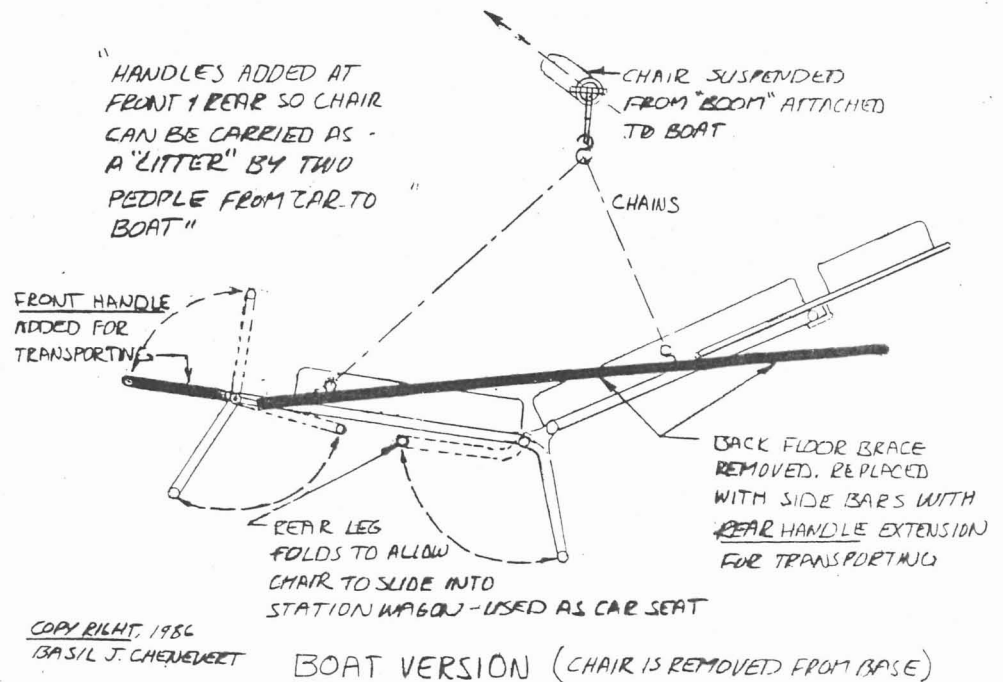
In preparation for sailing, the chair frame is removed from the wooden base, and carrying handles are added to the front and back. The adjustable back support is replaced with two bars, one on each side, that not only hold the chair back at a comfortable angle, but are equipped with chains so that the chair can be suspended from a swivel bar attached to a short boom mounted on top of the boat's cabin, extending over the cockpit. (See diagram on opposite page.)

With this arrangement, no matter how sharply the boat heels, the suspension system keeps me in the most comfortable seat on board, level with the horizon at all times.

continued on page 6



Basil Chenevert sailing aboard "The Second Wind" with his wife, Shirley.



An extra 24" length of hose allows the respirator to be stored on a counter inside the cabin just below the hatch.

With the rear leg folded, the chair slides neatly into the back of our small station wagon - with me in it - convenient for the trip to the marina or any other place we choose to go.

Address: Basil Chenevert, 819 Winchester, Lincoln Park, MI 48146. 313/381-5753.

IRON LUNG HISTORY IN JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION (JAMA)

Philip Drinker, ChE, and Charles McKhann, MD, developers of the first mechanical respirator, published an article in the May 18, 1929 issue of JAMA entitled "The Use of a New Apparatus for the Prolonged Administration of Artificial Respiration: I. A Fatal Case of Poliomyelitis."

The same article appeared as a Landmark Article in JAMA, March 21, 1986, followed by a Landmark Perspective written by Philip Drinker, PhD, and Charles McKhann, III, MD, sons of the two inventors, entitled "The Iron Lung: First Practical Means of Respiratory Support."

Both articles are fascinating and recommended reading.

KAUFERT STUDIES RESPIRATORY TECHNOLOGY AND PSYCHOSOCIAL ADAPATION

Joseph Kaufert, PhD, Dept. of Social & Preventive Medicine, University of Manitoba

In a paper presented at the Second Research Symposium on the Late Effects of Poliomyelitis in Warm Springs, Georgia, in September 1986, Joseph Kaufert examined the impact of changes in respiratory support technology upon the quality of life and current experience of aging effects among a selected sample of ventilator assisted polio survivors in Manitoba.

A series of in-depth interviews were conducted over an 18-month period with ten individuals who continue to be fully or partially assisted by mechanical ventilation. The interviews explored different dimensions of living with respiratory support, including individual strategies for managing respiratory insufficiency developed to maximize the benefits of technology while minimizing the psychological costs.

Following rehabilitation in the immediate post-acute phase, several of those interviewed became for the most part independent of respiratory support. All enjoyed a period of stability lasting several years before experiencing a decline in respiratory status. The diagnosis of inadequate ventilation heralded a new period of adaptation in which those polio survivors were forced to adjust anew to the constraints of respiratory technology.

For more information, write Joseph Kaufert, PhD, Dept. of Social & Preventive Medicine, University of Manitoba, 750 Bannatyne, Winnipeg, Manitoba R3E 0W3 Canada.

23 YEARS LATER:

AUSTRALIAN NOELENE HELEY STILL USES PORTABLE LUNG ON KANGAROO HUNTS

The 1963 issue of the Toomey j Gazette (now the Rehabilitation Gazette) featured Noelene Heley's portable fibre glass lung in an article which is reprinted below. The article offered instructions and blueprints. Requests for them were received from manufacturers and from other polio survivors in Canada, Mexico, New Zealand, South Africa, England, and all over the U.S.

Recently, Heley wrote, "Over the years I have enjoyed the Rehabilitation Gazette.... My small portable respirator is still in use, but holidays are not often because of aging parents....I have moved into a new hostel for the physically disabled with my tank respirator."

Address: Noelene Heley, Marlayna House, Eileen & Vidovic, Mildura 3500, Victoria, Australia.

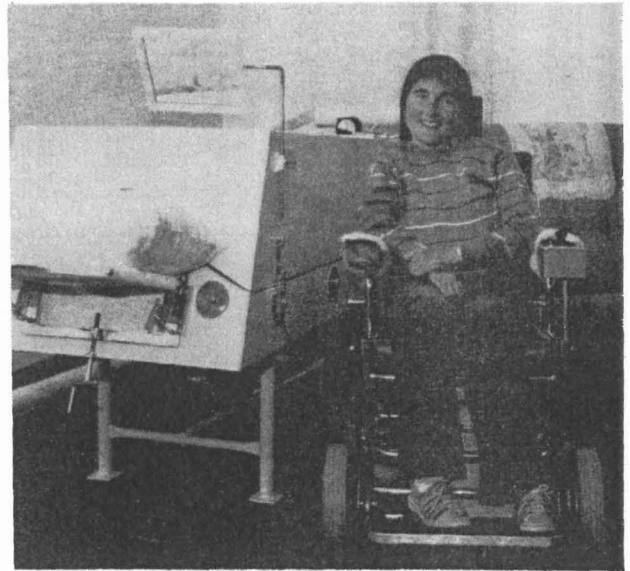


Photo: copyright Don Turvey

Noelene Heley in 1986.

● PORTABLE FIBRE GLASS LUNG ● This lightweight respirator was designed for eighteen-year old Noelene Heley to use at night on camping trips with her family on their kangaroo hunts and fishing trips.

It was developed and produced by Dr. Peter Colville of the Health Department with technicians and physiotheranists at Fairfield Hospital and the Royal Children's Hospital in Victoria, Australia.



Ready to leave for an Australian "roo shoot"

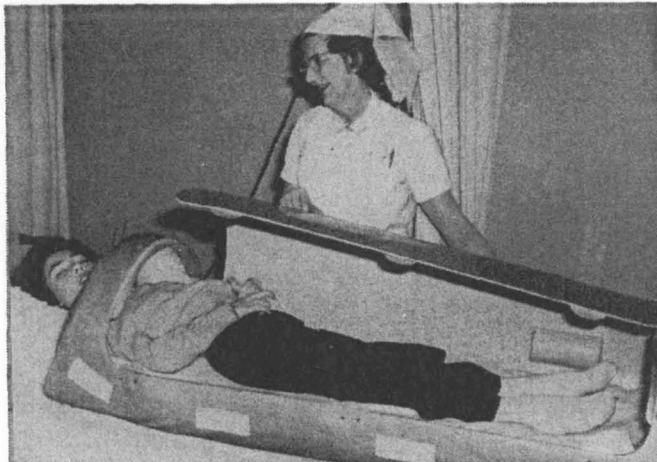


Photo: "The Age"

Noelene Heley

The lung, which looks like a space capsule, is really a "tank" tailored to size and shape. It weighs only 51 lbs. plus a 4" foam rubber mattress. A standard spiral twist type of collar is provided.

A mould was made to the required dimensions, the fibre glass applied, and the mould dismantled through the collar hole. The lid was then sawn out of the resultant barrel shaped shell and provided with aluminium clips for repositioning.

The seal is probably unique: simply a sheet of Plastic on Terylene laid over the shell - the suction creating a very good seal between the smooth sheet and the smooth shell; this sheet is positioned by several pieces of Velcro fastener.

A standard hospital type bellows is used. It is powered by a light vacuum cleaner motor or, when they leave the power lines, by a small petrol driven engine. The latter is used with about 30 feet of air hose and a large exhaust pipe submerged in water, so that the noise is subdued to tolerable levels.

(TjG has been furnished complete instructions and blueprints that we will send to anyone who wants to duplicate Noelene's Colville Respirator.)

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DEADLINE FOR NEXT ISSUE

Ventilator users and health care professionals are invited to submit articles. Please send material type-written and double-spaced. Deadline for Vol. 1, No. 2, is June 15, 1987.

1987 CALENDAR

February 6-7, 1987. ACCESS TO HEALTH CARE FOR THE VENTILATOR ASSISTED INDIVIDUAL. Hyatt Regency Dallas at Reunion, Dallas, Texas. Contact: American Respiratory Care Foundation, 1720 Regal Row, Suite 112, Dallas, TX 75235. 214/630-3540.

February 19-21, 1987. WORLD CONGRESS ON OXYGEN THERAPY AND HOME CARE. Marriott Hotel, City Center, Denver, Colorado. Contact: Webb-Waring Lung Institute, 4200 E. 9th Ave., Denver, CO 80262. 303/394-8231.

June 4-7, 1987. GINI'S FOURTH INTERNATIONAL POLIO & INDEPENDENT LIVING CONFERENCE. Sheraton St. Louis Hotel, St. Louis, Missouri. Contact: GINI, 4502 Maryland Ave., St. Louis, MO 63108. 314/361-0475. (See details below.)

October 15-17, 1987. FIRST INTERNATIONAL CONFERENCE ON ADVANCES IN PULMONARY REHABILITATION & MANAGEMENT OF CHRONIC RESPIRATORY FAILURE. Veruno (Novara), Italy. Contact: Redento Ferranti, MD, Gaylord Hospital, Wallingford, CT 06492.

RESPIRATORY POLIO SEQUELAE & CURRENT TREATMENT PANEL AT GINI POST-POLIO CONFERENCE

A distinguished panel of post-polio experts will discuss sleeping, breathing, and swallowing problems of polio survivors experiencing the late effects of polio during GINI's Fourth International Polio & Independent Living Conference in St. Louis in June. Face mask design and development will also be discussed at a special session.

Panelists include Augusta Alba, MD, Goldwater Memorial Hospital, D. Armin Fischer, MD, Rancho Los Amigos Hospital, Ernest Johnson, MD, Ohio State University Hospital, Oscar Schwartz, MD, St. Mary's Health Center, Redento Ferranti, MD, Gaylord Hospital, Susan Sortor, RRT, Dallas Rehabilitation Institute, and Hugh Newton-John, MD, FRACP, Fairfield Infectious Diseases Hospital, Victoria, Australia, and Geoffrey Spencer, OBE, MB, BS, FFARCS, St. Thomas Hospital, London, England.