

# IVUN. NEWS

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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.

## FACE MASK NETWORKING

An exciting session on face masks during G.I.N.I.'s Fourth International Polio and Independent Living Conference has led to a survey of ventilator users and to a new network within IVUN.

Susan Sortor, RRT, director of cardiopulmonary services at Dallas Rehabilitation Institute, is compiling an international inventory of devices used for nasal and oral ventilation. Her questionnaire has been sent to all who attended the face mask workshop at the conference and is reproduced in this issue of IVUN News so that others may respond. When all the questionnaires are returned, Sortor will compile the information and send it to all the respondents and to I.V.U.N. News.

Bud Blitzer, ventilator user in Los Angeles, sent a report to all who attended the face mask session at the G.I.N.I. conference entitled "A Progress Report for Positive (Pressure) Thinkers." Blitzer begins "Starting with the belief that a nose, mouth, or combined nose/mouth positive pressure system can improve the quality of many ventilator users' lives...we set off on an odyssey to evaluate and improve the available equipment. We found plenty of good ventilators around, but no really comfortable and workable production model masks. Therefore, we are concentrating our efforts on masks." Blitzer's report is summarized in this issue of IVUN News.

Bruni Bung, ventilator user in West Germany, also attended the conference, and brought her face mask design for inclusion in this newsletter.

The face mask alternative to the iron lung, rocking bed, and chest shell is being enthusiastically welcomed by both ventilator users and health professionals.

A PROGRESS REPORT FOR POSITIVE (PRESSURE) THINKERS  
Bud Blitzer, Los Angeles, California

"Since G.I.N.I.'s Fourth International Polio and Independent Living Conference in St. Louis in June, 1987, we have modified the standard Continuous Positive Air Pressure (CPAP) mask manufactured by Respiroics in Monroeville, Pennsylvania, by the addition of flexible foam padding to alleviate damage and discomfort to the face from prolonged use (8-10 continuous hours per night).

"We want to try other foam materials and densities before we can say we have a workable idea. We anticipate that custom masks at \$200-300 could be available quickly, and we will try to interest Respiroics in producing the mask at a much lower price.

"We have learned that Respiroics has a new full-face (nose/mouth) mask in the late stages of development. We do not know if it will be suitable for prolonged use.

"We have also learned that Puritan-Bennett has formally undertaken development of a face mask. We'll keep you informed.

"Adolf Ratzka, PhD, polio survivor and ventilator user in Sweden, has used a customized positive pressure face mask for several years. We have ordered a similar mask from Adolf's source to evaluate.

"With the assistance of Augusta Alba, MD, of Goldwater Memorial Hospital in New York City, we are trying the artificial nose humidifier made by Engstrom in Sweden, reputed to be more effective than the French nose."

Address: Bud Blitzer, 400 S. Saltair Ave., Los Angeles, CA 90049, 213/476-9343.

ED Note: Bud Blitzer, 61, contracted polio in 1952. He can generate a vital capacity of 750 lying down using his abdominal and neck muscles, a vital capacity of 1500 sitting up, and a vital capacity of 3500 frog breathing. Bud frog breathes during the day and evening, except for a 1-hour nap using a ventilator about 5:00 p.m. He uses a ventilator fulltime during the night.

Bud has used an iron lung, a rocking bed, a pulmo-wrap, a chest cuirass, mouth positive pressure ventilation, and nose positive pressure ventilation. He prefers a nose positive pressure system powered by LIFECARE's PLV-100 ventilator.



Bud Blitzer and Augusta Alba, MD

## THE FACE MASK ALTERNATIVE

Bruni Bung, Munich, West Germany

"I am 31 years old. I contracted polio in 1958 and during the acute stage, I had a tracheostomy for a few months. After that I did not need any ventilatory aids until I was 12 years old, when I used the iron lung during the night. I used the iron lung for the next 5 years, and then used a cuirass shell for the next 12 years. Two years ago, I began to sleep with a face mask.

"I got the idea of making my own mask during Gazette International Networking Institute's 1983 polio and independent living conference in St. Louis. Both Adolf Ratzka, PhD, of Sweden, and Darlene Odynski, RRT, of Canada were a great help to me.

"Made by a dentist and his technician, the face mask is of dental acrylic, consisting of a dental piece and a guard. The dental piece consists of 2 horseshoe-formed pieces cast from the upper and lower teeth. Such pieces are usually used to prevent someone from grinding his or her teeth. The 2 pieces are fused together leaving a gap at the front for air intake about 4mm high and extending across the incisors up to and including the canines. It is important that the dental piece allows the jaw to be in a relaxed position.

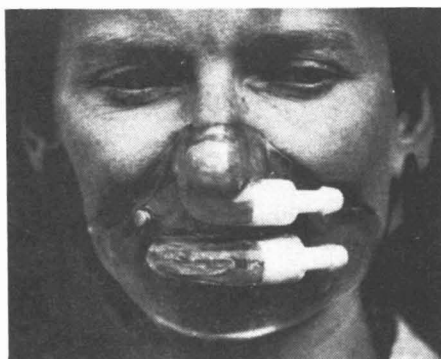
"A cast from the face is made using the same material as for the teeth. Before the cast can be removed from the face, it must be strengthened with plaster of paris. During the casting, one must hold the dental piece in one's mouth, otherwise the cast will not be exact. The face cast should be made when one is lying in a relaxed position, e.g., lying on a bed. The dental piece and the mask are then fused together with a special adhesive. To fix the mask in the proper position, I use a strap.

"My mask has two air tubes: one for the nose and one for the mouth, made of plastic tubing from intubation equipment. The boundaries of the mask are rounded off to avoid any sharp areas. Numerous fittings are necessary to eliminate pressure points and to minimize leakage.

"I use only the nose air tube because it is more comfortable and natural to breathe through the nose, and one doesn't need to learn to close the soft palate. I use my face mask with a Thompson Minilung and a heated humidifier.

"I think this face mask is the best alternative to using an iron lung, rocking bed, or chest shell during the night."

Address: Bruni Bung, Rumannstr.23, 8000 Munich 40, West Germany.



Bruni Bung and her face mask

# GPB for High Level Quads

Glossopharyngeal breathing (GPB) is commonly known as "frog breathing" because of the similarity between this method of breathing and that employed by amphibia. Basically, the mechanism of GPB is the same as that of a pump: the tongue and the throat act as a piston, and the mouth, the soft palate, and the larynx act as valves. There results an expansion of the lungs as air is pumped into them.

GPB has been used inadvertently for centuries by swimmers to fill their lungs with reserve air just before diving and by individuals with breathing difficulties. During the polio epidemics of the fifties some of the patients accidentally taught themselves to use GPB. When physiological studies proved its value, GPB was taught in respiratory centers around the world.

The best GPB teachers were other polio patients. Most people learned quickly by imitation or from word cues. GPB has been used extensively for more than twenty years by respiratory polio quads to produce adequate respiratory ventilation without the use of mechanical equipment—a sort of self-operated respirator. Some use it only while being transferred from one type of respirator to another; others use it during their waking hours when not using a respirator; and some use it for regular chest stretching and coughing.

In the fifties, Rancho Los Amigos Hospital was the leading proponent of GPB for respiratory polios. According to the book, *Quadriplegia After Spinal Cord Injury; a Treatment Guide for Physical Therapists*, written by staff members of the physical therapy department at Rancho, they are now using it with equal success with traumatic quads: "Glossopharyngeal breathing (GPB) is taught to patients with lesions at C4 and C5 and these patients are encouraged to use it routinely for chest expansion and cough force. Patients with lower lesions are taught GPB to provide a more effective cough force if, after orientation to the advantages of GPB, they express a desire to learn."

For high-level quads and others with respiratory problems, who could benefit from learning GPB, here are some of the more successful word cues of respiratory polio quads:

"Take a large breath and hold it while practicing the stroke. Be sure to pull the back of the tongue far down the throat on each stroke."

"After five years of trying I thought I would never learn to frog breathe. Then, once when 'goofing off' I imitated, in an exaggerated way, my friends I had seen doing it. Suddenly, I found myself laughing very loud laughs—I was frogging too!"

"Don't get the air in your stomach. You have to close

off your larynx. Don't move your Adam's apple, then you are swallowing. Leave your throat alone. Work with your tongue. The air goes down automatically."

"I close the back of my throat, just as one does when he pretends to have a cold in the nose."

"We used a hand bellows, the type used to pump up an air mattress. With this I was able to get the feel of air in my throat and enough pressure to close my larynx against."

"Try to scratch an itch on the back of your throat with your tongue so that you almost gag (SKIP the roof of your mouth)."

"Try to make believe you are blowing up a balloon, then follow through with the motion of dropping the throat muscles."

"On my imaginary straw I take a big swig of a yummy, thick, chocolate milkshake."

"I learned by continuously clucking my Adam's apple until I obtained a steady rhythm of taking in air."

"You have a big orange hanging in front of your mouth. Reach out with your lips and get it in your mouth, then move it around and then swallow it."

"As you gulp, hold your breath. It closes off the throat and keeps the air from escaping. Once you learn to do it the holding of your breath doesn't seem to come to mind."

"For a long time I have been trying to put down in words a simple way to explain GP breathing. Some of you may like to try the following: Put a straw in your mouth, then suck on it, using your mouth and tongue only to make the suction. Then after each time you draw in air, put the end of your tongue over the end of the straw to keep the air from escaping. Also, I've found that the front part or the tip of your tongue plays little part in GP breathing because I am able to hold my tongue between my teeth and, with my mouth closed, pump in air through my nose. This is a more advanced method, but it might give someone the clue."

"Anybody who has tried to learn 'Frog Breathing' will know that the main idea is to take a mouthful of air, seal it against your palate with your tongue and swallow it. I find that the more mouthfuls you take and the faster you take them, the better the lungful of

air. I usually take from four to six mouthfuls of air, hold it for a few seconds and then let it out. I have also found that if my top dentures are not very firmly in place, this can reduce the efficiency of my 'frogging.' So loose-fitting dentures are a definite drawback in learning to 'frog breathe'."

"After a while (when my neck had become stronger from sitting up in a wheelchair) I developed a method of using the accessory muscles of my neck to assist me in 'frogging.' While in the wheelchair, I could lift the very top part of my chest by throwing back my head and pulling very hard on my accessory muscles, at the same time gulping away as fast as possible."

"'Frog breathing' can be learned by practicing the following sequential steps: Inflate your lungs, normally, to your maximum inhale and hold your breath; close internal nasal passages; with mouth slightly open, pull tongue and larynx down to bring air into your mouth; close your mouth, think inhale, and press your tongue upward to compress the air trapped in your mouth. Air will pass into your lungs. Hold it! and repeat the last two steps several times before exhaling."

"Four suggestions: (1) If difficulty is experienced in closing the nasal passages, this can be learned by placing a mirror and light in a position which allows you to observe the movement of the soft palate at the back of the roof of your mouth. Experiment with moving your soft palate up and down. You can feel your nose become blocked when your palate is pressed upward, constricting the passage leading from the back of your throat into your nose. After you learn to 'frog' this becomes automatic. (2) It is not necessary to inhale normally before you 'frog' (Step 1, above). But, while you are learning, the first breaths you obtain will probably be of low volume, and if your lungs are filled to their accustomed amount before you 'frog,' you are more apt to notice the increase in pressure. (3) You will discover that by pushing your lower jaw forward in the mouth-open phase, and drawing it back in the mouth-closed phase, a greater volume of air will be inhaled. (4) Contrary to appearance, this is not swallowing air! If you swallow while holding air under pressure in your mouth, you will obtain a bloated stomach rather than inflated lungs."

"If you have the problem of losing air through the nasal passages, it is usually due to incoordination. Try the following method of closing the nose: First, with the nose clip on, practice GPB until it is performed easily. Second, if you have a quiet stroke, change it to a very loud and noisy one. Retain your tongue roll, but say 'up' at the same time you pull the tongue back. It will be a guttural sound. At first this may be difficult. Some persons say they can't do it, but have always

succeeded in the end. Keep this up until you can make a loud sound while stroking and still take in air. Next, practice cutting each stroke off in a staccato manner. Caution: Make sure you are filling your chest with air easily on each step before trying to proceed to the next one.

"Repeat the loud stroke and practice chopping it off until you can do it with ease and are obtaining enough air on each stroke to fill up readily. This may require from one to three weeks. Be sure you are putting effort into the stroke. Work at it as if you meant business. When this has been accomplished you may take off the nose clip and there should be no leaking. You can test with a mirror or feather."

"To my mind the only real problem is keeping the air out of the stomach and having it go and stay in the lungs. I think that if these possibilities are explained to the patient he will learn. You can feel where the air goes if it goes into the stomach and have him pretend to inhale as he forces the air out of the mouth. Niceties, such as taking the air in through the nostrils while the mouth is closed, can be learned later."

"The therapist would tell me to open my mouth, close it, and force the air back with my tongue several times in quick succession. . . . You can't just open and close your mouth and expect to start frog-breathing. You have to put some force into it and get the tongue in the habit of working in conjunction with the opening and closing of your mouth." Ω

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## HANDS-FREE TWO-WAY RADIO

Patricia O'Brien, ventilator user in Michigan, uses a voice-activated FM radio that enables her to communicate with another person up to a quarter-mile away. The small, lightweight radio is easy to use and reassuring for people with disabilities who might be alone at certain times. The Maxon Hands-Free Communicator (Model 49-SA) Compact FM Two-Way Radio costs about \$60 from Maxon Systems, Inc., 10725 Ambassador Dr., Kansas City, MO 64513 or Pecar Electronics, 11201 Morang, Detroit, MI 48224.

Address: Pat O'Brien, 1304 McLean, Royal Oak, MI 48067.

## FAMILIES OF SPINAL MUSCULAR ATROPHY (SMA)

Founded in 1984 by Melanie Ferrand, mother of a son with spinal muscular atrophy, Families of Spinal Muscular Atrophy (SMA) seeks to promote research into the treatment and causes of Werdnig-Hoffman disease, Kugelberg-Welander disease, benign congenital hypotonia, and Aran-Duchenne muscular dystrophy. There are approximately 6000 children in the United States today with some form of SMA.

Address: Families of SMA, P.O. Box 15455, New Orleans, LA 70175, 504/561-8713.

## USED VENTILATORS NEEDED FOR MEXICO

Douglas Hewitt, a volunteer with Project Projimo, a non-profit organization working with people with disabilities in western Mexico, is collecting all types of used ventilatory and orthopedic equipment to be redistributed and reused by people in rural Mexico. Any kind of ventilator or orthotic aid in good condition may be shipped to Hewitt at P.O. Box 128, 14695 Poncho Conde Circle, Rancho Murietta, CA 95683, 916/354-2934.

## WARNING: ANTI-DIARRHEAL MEDICINES CONTAINING NARCOTICS

Pulmonologists and respiratory therapists are becoming increasingly concerned about the use of anti-diarrheal medicines containing narcotics by individuals with paralysis of the trunk muscles or diaphragm. These medicines may decrease the respiratory drive, especially in debilitated people who may be more sensitive to respiratory depressant effects. These people may also have less body mass that could possibly cause them to have a stronger adverse reaction to the medicine.

"Travellers with disabilities are urged to carefully read the labels on anti-diarrheal medicines that often contain narcotics, such as Lomotil, paregoric, etc.," says Susan Sortor, RRT, Dallas Rehabilitation Institute. Sortor has treated two polio survivors who returned from Mexico in respiratory distress as a result of taking Lomotil without realizing that it contained a narcotic.

Oscar Schwartz, MD, St. Mary's Health Center in St. Louis, advises that travelers take along Pepto Bismol or Kaopectate. If the diarrhea lasts longer than 48 hours, one should see a physician due to the risk of dehydration.

CATCH-22 FOR HOME CARE FOR VENTILATOR ASSISTED CHILDREN  
Jane Armfield, Colma, California

"Susie, our fourth daughter, was born December 19, 1985, apparently a normal, health baby. However, in January 1986, she stopped breathing, and was diagnosed as having Ondine's curse (central hypoventilation). In May 1986, Susie underwent a tracheostomy for mechanical ventilation. She is able to tolerate short periods of time off the ventilator while awake, but she will need to use mechanical ventilation all her life.

"Initially, our insurance had a lifetime benefit of \$500,000 and only a yearly provision of \$1500 maximum for home care. The discharge planner from Children's Hospital in San Francisco convinced the insurance company that it would be more cost-effective for Susan to go home with 24-hour care than to remain in the hospital intensive care unit.

"California's Children's Services agreed to be a secondary payer for equipment costs only after the insurance was exhausted, and would not agree to any commitment for long-term acute nursing care. Susie qualified to receive SSI payments during her hospitalization, but did not qualify for SSI as soon as she was discharged from the hospital, because our income was too high.

"The Department of Developmental Services agreed to provide 240 hours of RN level respite care, and later we convinced them, with the assistance of Protection & Advocacy, Inc., a state agency mandated to protect the rights of individuals with developmental disabilities, to double the hours to 480 per year. Meanwhile, my husband's employer advised us that we could switch to an HMO that would not pre-exist Susie's condition and that had no limit on hospitalization. However, the HMO had never covered a ventilator assisted child at home, and they would not provide enough respite nursing care.

"This is just an outline of the problems we encountered in dealing with the different agencies. The basic issue is that home care at the acute level is still not legitimized to the fullest extent by government agencies or insurance companies. No one payer was able to provide what was needed, and the lack of coordination between the agencies and insurance companies precluded any attempts to provide what was needed. And there are never-ending demands by all parties to justify Susie's needs. Everyone must realize that Susie's condition is not going to change or get better. She is either going to be ventilator assisted or a candidate for phrenic nerve pacing, so why must we continuously justify her need for nursing care?"

Address: Jane Armfield, 544-87th St., Colma, CA 94015.

ED Note: Jane Armfield testified before a federal task force on technology-dependent children in San Francisco



Susie & Jane Armfield

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**MONAGHAN 170-C's  
WANTED**

LIFECARE wants to purchase any used Monaghan 170-C ventilators. Standard offer is \$300 per ventilator. Contact Geoff Waters at LIFECARE, 655 Aspen Ridge Dr., Lafayette, CO 80026, 303/666-9234.

**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. 2, No. 1, is Nov. 17, 1987.

**1987 CALENDAR**

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, 203/269-3344.

**1988 CALENDAR**

March 2-5, 1988. INTERNATIONAL CONFERENCE ON PULMONARY REHABILITATION AND HOME MECHANICAL VENTILATION. Marriott Hotel, City Center, Denver, Colorado. Contact: Louise Nett, RN, RRT, Webb-Waring Lung Institute, 4200 E. 9th Ave., Box C321, Denver, CO 80262, 303/394-7918.

**VENTILATORS AND MUSCULAR DYSTROPHY - NEW G.I.N.I. PUBLICATION**

Ventilators and Muscular Dystrophy by Nancy Schock, M.A., and Agatha Colbert, M.D., is a new handbook published by Gazette International Networking Institute (G.I.N.I.).

The handbook discusses how to make an informed choice about mechanical ventilation in extending the lives of persons with Duchenne muscular dystrophy (DMD). Physicians, health care professionals, community service workers and persons with DMD and their families have contributed short articles on the advantages of mechanical ventilation. A bibliography and glossary are appended to the 40-page handbook.

Author Nancy Schock is the mother of a son with DMD, and Agatha Colbert, MD, is chief physiatrist and director of the Muscular Dystrophy Clinic in Lakeville, Massachusetts.

Ventilators and Muscular Dystrophy is available for \$6 postpaid from G.I.N.I., 4502 Maryland Ave., St. Louis, MO 63108. (Bulk orders are available at lower per copy prices.)