

INTERNATIONAL VENTILATOR USERS NETWORK

I.V.U.N. NEWS

Fall 1996 ■ Volume 10, No. 2

I.V.U.N. NEWS CELEBRATES 10TH ANNIVERSARY

I.V.U.N. News first appeared in 1987, and now, 10 years later, the newsletter has broadened its scope and reach, evolving into a highly specialized publication, prized for its combination of straight-forward information by ventilator users and health professionals alike.

Networking among ventilator users, pulmonary physicians, nurses, respiratory therapists, and ventilator equipment manufacturers and dealers is reflected in each issue of *I.V.U.N. News*. The newsletter balances information on the latest in nasal/ facial masks, communication with a tracheostomy tube, and warnings about under-ventilation with stories about sailing, sky diving, and intercontinental travel. I.V.U.N.'s ventilator users include the old pros: polio survivors, people with high spinal cord injury and muscular dystrophy, as well as the new pediatric population — children with BPD, CCHS, Pompe's disease, etc. The annual directory of home ventilation experts comprises a truly international network.

A prime example of I.V.U.N. networking occurred last May. Annelie Coetzee of South Africa contacted Joan Headley in the G.I.N.I. offices requesting help in expediting the repair of her Companion 2800. Coetzee has idiopathic scoliosis and uses her ventilator during the night. She wrote "... I have a Companion 2800 ventilator which I bought in 1989. It has never given me any problems, but three days ago, it broke down. The problem was eventually found to be a faulty circuit board. The local agent of Puritan-Bennett told me that it could no longer be repaired and that I must trade it in for a Companion 2801 ...

"I am really desperate to have the ventilator repaired as I do not have the means to buy a new one. Due to the state of our country's economy and the poor exchange rate, ventilators cost the earth here. (I paid R20,000 in 1989 — equivalent to \$5,000US today — which was then the equivalent of my gross annual salary as a translator.) My medical insurance also only pays out R2500 per year for medical appliances such as ventilators."

Headley contacted Puritan-Bennett in the U.S., determined that the Companion 2800 could

indeed be repaired, and faxed Coetzee the phone numbers of Puritan-Bennett in London and Andre Thobois, a medical equipment repairer in Johannesburg. Coetzee replied, "I am glad to say that the matter with my Puritan-Bennett Companion 2800 has now been resolved and that Puritan-Bennett in London has done more than I ever hoped for. Mr. Thobois told me that he had just spoken to Mr. Chapman of Puritan-Bennett in London and Mr. Chapman said that they had decided to do a trade-in on my machine. They would give me a demonstration model Companion 2801 with only 1,000 hours in exchange for my ventilator which has already done 16,000 hours. My old ventilator would then be repaired and kept in Cape Town for a backup. All this would be free of charge. Needless to say, I was so surprised I was speechless.

"... A follow-up visit by the regional manager of Puritan-Bennett, Mr. Featherstone, answered my questions and gave me the assurance that the Companion 2801 was still manufactured in Europe and would be serviced for some time to come. Both he and Mr. Chapman have been extremely kind and helpful. I have not yet received the Companion 2801, but Mr. Thobois has in the meantime been able to repair my old ventilator and return it to me. After sleeping with a strange and noisy ventilator for a month, it is heaven to have my own trusted ventilator back. Thank you again for your help."

I.V.U.N. News looks forward to the next 10 years of networking and its special role in connecting people with people.

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CCHS DATA

Mary Vanderlaan, PhD, founder of the CCHS Family Support Network, collated data on 94 cases of congenital central hypoventilation syndrome (CCHS) in the United States and Canada. She presented a preliminary analysis of the data at the First International CCHS Symposium, held in May 1996 in New Orleans. (Abstracts from the symposium will be published in a supplement to *Pediatric Pulmonology* in 1997.) Dr. Vanderlaan's data is part of a larger study of health care regimens and issues among CCHS children. A portion of the data reveals some interesting statistics below.

Dr. Vanderlaan's son Nico, who has CCHS, just entered third grade and is at the top of his class. He recently switched to nasal ventilation and had his trach closed. Dr. Vanderlaan can be contacted at 71 Maple St., Oneonta NY 13820 (607/432-8872, e-mail: Vanderlaan@hartwick.edu).

Population profile:

Male	55%
Female	45%
Birth - 5 years	29%
6-10 years	36%
11-15 years	27%
16-23 years	9%

Ventilators:

Home vent via trach	67%
Nasal bi-level IPPV	14%
Phrenic pacer/vent/trach	10.6%
Neg. pressure	5.3%
Phrenic pace	3%
Backup vents	58%
Equipment failure	82%
Equipment malfunction	77%
Worries about equipment	62%

Nursing support at home:

Night nurse	58.5%
25-60 hrs per week	24%
61+ hrs per week	36%

Payment for nursing:

Private health insurance	38%
Medicaid	25%
Insurance + Medicaid	37%

Family issues:

CCHS child in family	95%
viewed as positive experience	
Care easier over time	92%
by 1-2 yrs	20%
by 3-5 yrs	43%
by 6 yrs	29%
Marital stress	71%
Separation/divorce	16%
Affected decision to have	53%
more children	
Retaining health coverage	83%
has limited mobility	
Affected parents' social life	78%
Parents regularly cancel	48%
events	
Stress for siblings	48%
Affected vacation/recreation	81%
Affected travel modes	69%
Air travel w/CCHS child	55%

MOVING?

Please send both your old and new addresses
to:

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International Ventilator Users Network (I.V.U.N.)

*links ventilator users with each other and
with health care professionals interested
in home mechanical ventilation.*

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CHOOSING LIFE, EVEN ON A VENTILATOR

■ Assisted suicide:

Terminally ill people — not doctors or families or counselors — should determine their own fate.

by Robert C. Horn III

In the national debate on doctor-assisted suicide, we have heard from judges and lawyers, doctors and clergymen, ethicists and editorial writers, politicians and pundits. The one group conspicuously absent so far from the discussion is the one most affected by its outcome: the terminally ill.

I am one of the terminally ill. In 1988, I was diagnosed as having amyotrophic lateral sclerosis, commonly known as Lou Gehrig's Disease. ALS is a degenerative neuromuscular disease that swiftly robs the victim of voluntary muscle control, including those necessary for breathing. The average life expectancy after diagnosis is two to four years. ALS does not affect the mind, so one is perfectly aware of his or her physical deterioration. By the end, the individual typically is unable to move, talk above a whisper, eat without choking, or breathe without difficulty.

ALS is a terminal disease. It is progressive, unrelenting, merciless. Its endgame is inevitable. Shouldn't a person faced with such prospects have the legal right to choose whether to go on with life or end it with dignity? ALS victim Dennis Kaye, in his book *Laugh, I Thought I'd Die*, writes that he does not want to go on a ventilator when it becomes necessary. Why should he have to? In *This Far and No More*, another book about a personal struggle with ALS, Emily Bauer (a pseudonym) poignantly wrote in her diary: "I don't know how anyone with access to a normal life can expect me to accept such a limited one. That others have accepted a drastically limited life does not mean that is the right course of action for me." Who has the right to tell Emily that she doesn't have a choice?

Life is about making decisions and choices. For the terminally ill, those choices should include when to die. This doesn't mean choice by doctors or family members or ministers or counselors or any person except the patient himself. Others can and should be consulted, but the decision must be up to — in the words of the U.S. Ninth Circuit Court of Appeals — the "mentally competent adult" patient.

But the right to choose death necessarily must include the right to choose life. I was faced with that choice in February 1991. In less than three years, I had gone from a robust, physically active person to being completely disabled. I could barely squeeze out a sound, had lost more than a third of my body weight because I had trouble swallowing even mushy foods, was almost totally paralyzed, and my breathing had become very labored. What to do?

I am fortunate in that I had a real choice. Two doctors separately offered me the option of ending my life painlessly. I didn't choose that option, but I deeply appreciate their compassion. I made a conscious decision to go on a ventilator and on with my life. I talked it over with several people close to me, especially my wife, who would take on the additional role of caregiver. But I alone made the decision. I chose life.

After five years of being tethered to a ventilator, "eating" via a tube in my stomach, "talking" with my eyebrows, and operating the computer with my foot, did I make the right choice? You bet! What I have left is more valuable than what I have lost. The things I can do are more important than those that I can't. There is much more to life than physical ability. I am still a vibrant, healthy and independent person mentally, emotionally, and spiritually. I think, reason and analyze, remember, read, write, learn, and communicate. I can love, feel happiness and sadness, be enthusiastic, get angry, feel joy. I can believe, hope, and have faith. That

adds up to an extensive list of things I can still "do" in spite of my disease.

Although I made the right decision for me, that is not to say that my choice would be appropriate for everyone. The personal struggles of people against life-threatening illnesses do not lend themselves to facile judgments. These are highly individual battles that depend on many factors, from personal outlook and philosophy to the specific circumstances and, significantly, to the nature of the illness itself. For instance, in ALS, the symptoms vary dramatically from patient to patient; one person's experience is no guide to someone else's.

That said, I still would like to talk to those people who are seeking to end their lives — and would have liked to talk to those who did. What would I say? I would simply tell them that there is life on a ventilator. I have found that despite the difficult conditions of disability and terminal illness, life can be meaningful, productive, fulfilling, rewarding, and valuable. I defend their right to die, but I also affirm their right to live.

For me, having a choice is the key. No one forced me to live. No one forced me to die. I chose. Because of that, I can cope with the negatives and "downs" as well as relish the positives and "ups" that my life presents. Choice makes all the difference; it's as simple and as complicated as that.

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Robert C. Horn, III, PhD, is professor emeritus of political science at CSU, Northridge. He is a Russian scholar and has authored many articles and books on the former Soviet Union and its relationship to countries in Southeast Asia.

Dr. Horn's latest book is more personal — How Will They Know If I'm Dead? Transcending Disability and Terminal Illness, published this fall by St. Lucie Press (see insert).

LIVING WITH POMPE'S DISEASE

by Mary Garrett

Our son, Lucas Garrett, the youngest of our four children, was born July 23, 1993, and was diagnosed with Pompe's disease (see below) at five months. In Luke's case, his respiratory and skeletal muscles are affected. After several bouts with pneumonia and a stomach virus, which led to dehydration, Luke suffered complete respiratory failure in March 1995. He was trached and ventilated that April and spent 63 days in the pediatric ICU at Albany (NY) Medical Center Hospital. Luke's condition improved using the hospital ventilator, but did not respond as well when attempts were



made to transfer him to a home ventilator. The BiPAP® system was tried, and he flourished; however, BiPAP® is not intended for longterm use. Luke was finally discharged in May 1995 with a unique setup. He uses an LP10 with a Remstar CPAP added through the back to give him a continuous flow round the clock.

Leaving the safety net of the ICU was difficult, but we were anxious to return home to our other children. Little did we know then how hard we would have to fight ... for just about everything.

Our HMO denied us a second backup ventilator. Their reasoning was that we lived very close to our local hospital and if any problems developed we could take him there. This was unreasonable because the hospital is not equipped with a pediatric ICU and does not take children who use ventilators. Luke would require stabilization there and then be transported to Albany, over 60 miles away. Also, he would have to be ambu-bagged this entire time. After several weeks and many letters and phone calls, we won our battle with the HMO and were granted the backup ventilator.

We have become very strong advocates for our son, and are truly saddened by the struggles that have to be surmounted in order to obtain what he needs. We don't feel that we should face so many obstacles. We are very fortunate to have a great support team comprised of our family, five nurses (20 hours per day, the same five who have been with us for a long time), physical and speech therapists, a special education teacher, and an early intervention coordinator. Continuity of care is very important.

We have learned that many people, professionals included, have grave misconceptions about children who use ventilators. Luke is a very bright and loving child. With his Passy-Muir Tracheostomy Speaking Valve (which he wears continuously during his waking hours), he is becoming an accomplished speaker. His favorite phrase of the moment seems to be, "I want that!" Luke is quite normal for his age, just extremely weak. He is very tolerant and forgiving of everything that we do to him. Luke has managed to stay out of the hospital since his discharge last May. His backup ventilator

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Pompe's Disease/Acid Maltase Deficiency

Glycogen storage diseases of muscles are rare autosomal recessive diseases, that can be clinically mild or severe. The more severe Pompe's disease, glycogen storage disease-type II, is usually fatal in children by age 2. These children lack the acid maltase enzyme that breaks down glycogen and converts it to fuel. The stored glycogen destroys muscle cells. The adult-onset disorder, referred to as acid maltase deficiency, commonly presents with hypoventilation due to respiratory muscle involvement. There is progressive generalized motor weakness resembling limb girdle muscular dystrophy. People with acid maltase deficiency may be able to walk and to work, despite the respiratory complications. They can be supported for a lifetime by noninvasive ventilators (negative or positive systems, rocking bed). Each individual may have a different support system based on individual characteristics and needs. Some use two systems; one for sleeping and another while awake.

(Thanks to Norma Braun, MD, for her review.)

LIVING WITH ACID MALTASE DEFICIENCY

by Larry Homolka, PhD

I did not anticipate respiratory problems in 1983 because when first diagnosed, I was not told. I was left with the impression that I had Becker's muscular dystrophy, not acid maltase deficiency (see page 4). In 1986, an MDA secretary let the cat out of the bag. I was very angry at the sloppy treatment from a famous medical center in New York. This led me to two important conclusions. One, that you should demand a copy of your medical chart, especially the diagnostic summary, and combine thorough reading with independent and personal research. Two, that some physicians are careless and ignorant of recent research, and have little at stake when the disease has no therapy or cure. Some, of course, will try new leads or at least will offer a little human concern. (A real life joke: When I appeared in 1986 before a neurologist at a famous medical center he asked, "Do you have a tracheostomy?" I replied, "No, can't you see?" It was July, the temperature was 90°, and my shirt was open mid-chest. This was the first I had heard of trachs used for muscular dystrophy — what an introduction.)

I had no idea what a ventilator was until I was fitted out with a nasal mask by a pulmonologist in 1990. I liked it — assisted breathing that I could control. The pulmonary doctors I encountered were noncommittal. One said I could try nasal ventilation for a couple of years or simply, "Let nature take its course." I think the medical establishment should, however, err on the side of encouragement; "Yes, do it. Stay alive." I have no doubt that without the ventilator I would now be dead. Fortunately, my Medicare had just kicked in, so I could also finance the ventilator rental easily.

Since 1990, I have made a few modifications of my own. I use a nasal mask with an LP10 at night. During the day, I need mouth intermittent positive pressure ventilation (MIPPV) for 3-4 hours or more. I re-use an artificial nose, modified for oral use by flattening the end like a cigar. It can be softened by squeezing in vice pliers after being warmed on the stove. I made my own adaptation with an ambu bag by attaching an extra piece of blue circuit to the ambu bag. When standing and talking on the phone and using MIPPV, I hook the exhaust valve around my Medic Alert chain — like a neck microphone on a chain — so the mouthpiece can be reached or spit out while talking. It frees the hands.

I continue to work as an artist, but it is difficult to stand to paint, so I have moved to smaller scale works. It is just as satisfying, maybe more so, although the market place likes BIG, usually. I have used my limitations to an advantage. I live alone.

I always make sure an ambu bag and a phone are at hand, because fear and panic are my real enemies. I take a moderate tranquilizer to deal with anxiety about shortness of breath. I can walk in my apartment with the aid of a cane, but use an electric scooter outside. I expect

to become increasingly dependent. I need more air more of the time.

We surprise ourselves, I think, regarding just how much discomfort and change we can absorb regarding "disabled living." My art and my thinking have never been better, after too many years of muddling along as a college professor. Now I have less energy and fewer opportunities to waste. I am still able to accomplish some important things personally, be it a full scale art exhibit or



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Larry Homolka was born in 1941. He majored in art at Grinnell College and was awarded a graduate fellowship to Harvard where he earned a doctorate in fine arts, specializing in modern architectural history. He has lived and worked in New York City since 1967. Homolka's paintings have been selected for various private and corporate collections in the United States, Germany, Spain, and Brazil. His last one-man show in New York was held in 1994.

and Remstar are on his wheelchair, and he very much enjoys his mobile status.

We have so many questions, which Luke is too young to answer. We would like to know what a trach change feels like, and if it hurts. We would also like to know if the saline that we use during suctioning burns or drowns him. We would like to know what suctioning feels like, and if the trach is uncomfortable when we lay him on his stomach. We would like to correspond with other families of pediatric ventilator users to learn some of these answers.

ADDRESS: The Garrett Family, 3 Wing St., Glens Falls NY 12801 (518/798-3719).

Pompe's disease is a progressive disease and we pray our son stays well enough until a cure or at least a curative treatment can be found. We are working very hard to support the very promising enzyme replacement research being done at Duke University in North Carolina. We have established "The Lucas Garrett Pompe's Foundation, Inc." to help fund this research. Contributions can be made out to the Foundation and mailed to 3 Wing St., Glens Falls NY 12801.

ACID MALTASE DEFICIENCY Continued from page 5

finding a new way to get out of bed or go to the bathroom. I read several disability periodicals searching for ideas and new products.

Current ventilators seem to me unnecessarily large, noisy, and heavy. Such medieval machinery, with crude tubing, circuits, and other appliances, may frighten some people enough to "Let nature take its course." The equipment is not high-tech enough. Where is the research into better ways of artificial breathing? I think some of my friends harbor a latent "tube-phobia" which I understand but do not support. In this age of government take-aways and Kevorkianism, we need a compassionate and activist medical profession and groups such as the MDA to fight for patients' lives. Ventilators, after all, are life savers.

ADDRESS: Larry Homolka, PhD, 61 Jane St., #14N, New York NY 10014.

SCHOOLS AND PROGRAMS FOR PEDIATRIC VENTILATOR USERS

The Bancroft School at Voorhees Pediatric Facility in Voorhees, New Jersey opened in July 1995. The first state-approved, nonprofit private school in a pediatric subacute care facility, Bancroft currently serves 76 children between the ages of 3 and 20 who are chronically ill, technologically dependent, and require continuous nursing care. Of the 76 children enrolled, nine of them are ventilator users. There are five classrooms specially designed to accommodate them, each with its own nurse. Staff includes a principal, teachers, teaching assistants, and a school social worker who together develop an individualized plan for each student.

Bancroft provides different levels of classroom instruction each day — four hours or two and a half hours or tutoring for one to two hours per day. The goal is for students to improve their cognitive, social, emotional, and adaptive abilities so they can be discharged from the facility and return home. Emphasis of instruction, developmentally sequenced, is focused on motor skills, sensory processing skills, self-care skills, socialization and communication skills, academic/cognitive skills, and pre-vocational skills. Related services are offered in speech, language, occupational, and physical therapies, and psychological and social services. For more information about Bancroft, contact Terry Lichty, Principal, 609/566-0634.

Ken-Crest Services, affiliated with the Evangelical Lutheran Church in America, provides several opportunities for technology-dependent children in the Philadelphia area. Ken-Crest offers preschool programs for medically fragile children and day care and foster homes for pediatric ventilator users. The highly-trained staff of teachers, therapists, and pediatric nurses work with each child individually, encouraging intellectual, physical, and social development. Infants and children demonstrating developmental delays or who have complex neurological, orthopedic, respiratory, or other medical conditions are eligible. The program is funded by public sources and private grants and is without cost to the family. For more information about Ken-Crest, call 610/825-9360 (or e-mail centers@libertynet.org).

1996 I.V.U.N. DIRECTORY

Long-time ventilator users and health professionals who are experts about and advocates for home mechanical ventilation are listed. Send additions, deletions, and corrections to: I.V.U.N., 4207 Lindell Blvd., #110, St. Louis, MO 63108-2915 (314/534-0475, FAX 314/534-5070, or e-mail: gini_intl@msn.com).

★ ventilator user

▲ health care professional

* ventilator users organization

■ pediatric ventilator user

▼ pediatric health care professional

● pediatric ventilator users organization

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Richmond VA 23237
804/275-8425 804/271-8261 FAX

Lawrence C. Becker ★

9244 Waterfall Drive
Roanoke VA 24019
804/229-7009 804/229-8621 FAX

Washington**Susan McInturff, RCP, RRT ▲**

Farrell's Home Health
2326 Wheaton Way
Bremerton WA 98310
206/377-0164 206/377-8782 FAX

Jerry Daniel ★

VENTEK
4604 Plomondon
Vancouver WA 98661
360/693-9013

West Virginia**David Cummons**

West Virginia Support Group for
Ventilator Dependent Individuals
and Families ●
709 Clinton Ave.
Charleston WV 25302
304/345-6228

Wisconsin**Gail Genereau ★**

910 E. Sylvan Avenue
Appleton WI 54915
414/734-1452

Betty J. Mielke ★

933 Windsor Ave.
Fond Du Lac WI 54935

Kathy Easland, RRT ▲

University of Wisconsin Hospitals
600 Highland Ave
Madison WI 53792
608/263-7040 608/263-1987 FAX

Mike Luber ★

6920 N. Barnett
Milwaukee WI 53219
414/352-2185

June Price ★

Living SMARt
3576 S. 43rd St., #32
Milwaukee WI 53220-1550
414/541-2848 (same for FAX)
LiveSMARt@aol.com

Mark Splaingard, MD ▼

Children's Hospital
PO Box 1997
Milwaukee WI 53201
414/266-2902

Japanese Ventilator Users Network (J.V.U.N.)

"We at J.V.U.N. are a new organization which has just started. For six years we have been producing a publication for ventilator users called *Another Voice*. Now we have 30 full members and 300 associate members who have an interest in this network. These people include specialists in social security, welfare, and medical treatment. At present four of the full members live on their own as members of the community. One more person who has been living in hospital is about to start an independent life."

Kimiyo Satoh

NEW EQUIPMENT & AIDS

Monarch Mini Mask, Respironics Inc., 1001 Murry Ridge Dr., Murryville PA 15668-8550. 800/345-6443 or 412/733-0200. FAX 412/733-0299. [Http://www.respironics.com](http://www.respironics.com).

J.L. of Florida writes, "The Monarch mask seems to be comfortable and I can sleep throughout the night. I would recommend that people who are having trouble with other mask devices give it a try."

PB 335 Respiratory Support System, Nellcor Puritan Bennett, 4280 Hacienda Dr., Pleasanton CA 94588. 800/248-0890 (press 4). FAX 510/463-4500.

From the CCHS Family Newsletter, July 1996, Mary Vanderlaan writes, "Some of the features of the PB 335 make it a nice alternative to the Respironics BiPAP® system. For one thing, the PB 335 has alarms for disconnect. It also has pressures up to 35 versus the 20 of BiPAP. (That is a useful feature should a child have pneumonia and need pressures higher than 20.) Moreover, the settings lock in on the PB 335, whereas many of us have been seeing the settings on the BiPAP® system 'drift' with machine movement or over time. The control dials are on the front of the machine, making it a bit more user-friendly."

Hayek Oscillator, Breasy Medical Equipment (US), Inc., 4116-B Rose Lake Dr., Charlotte NC 28217. 800/845-8606. FAX 704/357-3413. Breasy Medical Equipment, Ltd., Breasy Place, 9 Burroughs Gardens, London NW4 4AU, U.K. 44-181-203 6877. FAX 44-181-203 4758.

A new, noninvasive, negative pressure ventilator consisting of a clear plastic cuirass, power unit, and keyboard control unit. The device can ventilate adults, children, and infants by oscillating the chest wall around a negative base line. Key advantages are: 1) the spontaneous expulsion of secretions, rather than using conventional physical therapy techniques; and 2) use in microlaryngeal surgery. The equipment costs \$11,000 plus servicing; however, Breasy offers many kinds of rental plans and lease/purchase options.

RoEzIt®, LuSal Enterprises, Inc., Rte. 4, Box 4189F, Athens TX 75751. 800/426-7139. 903/479-3155. FAX 903/479-3608. RoEzIt® is a skin moisturizer to treat irritation and chafing associated with CPAP mask use. It combines the unique properties of aloe and emu oil. Retail price is about \$7.95 per

tube, available from home health care dealers. *I.V.U.N. News* readers who find this product helpful are asked to write *I.V.U.N.*

Electronic Speech Enhancer™, Electronic Speech Enhancement, Inc., 1115 Ridge Rd., St. Louis MO 63021. 800/600-9819 or 314/394-0770. FAX 314/394-9442. A lightweight, battery-powered device that clarifies speech electronically. People speak into a special microphone and their own voices come out instantly, sounding like them, only clearer. It enables the individual to be better understood, and particularly people who use ventilators. The microphones can be hand-held or used with a special headband. The device costs less than a synthesizer board, and has only an on-off switch. Cost ranges from \$2,000-3,500 and is covered by many insurance carriers.

LIFECARE SOLD TO RESPIRONICS

LIFECARE International, Inc., announced in late August that the company entered into an agreement to be acquired by Respironics, Inc. As most ventilator users know, LIFECARE, under the leadership of President James C. Campbell, is a leading international developer, manufacturer, and marketer of portable ventilators.

Respironics, best known for its BiPAP® systems, benefits from LIFECARE's district offices worldwide and its strong staff in sales and field technical services. The sale is expected to be final by October 1996.

DEADLINE ...

for submission of articles, stories, information, etc. for the Spring 1997 issue of *I.V.U.N. News* is March 1, 1997.

Please mail, FAX, or e-mail:

I.V.U.N. NEWS
4207 Lindell Blvd., #110
St. Louis, MO 63108-2915 USA
FAX 314/534-5070
e-mail: gini_intl@msn.com

■ **LIVING SMART** is a bimonthly newsletter for adults with spinal muscular atrophy. A complimentary copy is free for the asking to *I.V.U.N. News* readers. Contact June Price, Editor, Living SMART, 3576 South 43rd St., #32, Milwaukee WI 53220-1550 (414/541-2848, e-mail: LiveSMART@aol.com).

■ **THE REEVE-IRVINE RESEARCH CENTER**, part of UC Irvine School of Medicine, is involved in fundraising for spinal cord research. To make contributions, make your check payable to The Reeve-Irvine Research Center, and send to UCI Advancement, 4900 Berkeley Place, Irvine CA 92697-5605.

■ **HIGH QUADRIPLEGIA**, the winter issue of *Topics in Spinal Cord Injury Rehabilitation*, covers many subjects and, of course, quality of life issues including a section of consumer perspectives. The issue is \$21.00 (shipping & handling is free if a charge card is used — if not, add \$2.00). Call Aspen Publishers, Inc., 800/638-8437.

■ **EXPLORING BREATHING SUPPORT OPTIONS**, a conference held in April 1996, is now available on 20 videotapes from the Citizens for Independence in Living and Breathing (CILB). Subjects include management and decision-making in ALS, assisted breathing and coughing techniques, management of respiratory infections, ethical and quality of life issues, and invasive and noninvasive ventilation in neuromuscular disorders. The tapes range from 25 minutes to 75 minutes long. The price for each videotape ranges from \$19.95 to \$29.95 and there is a 10% discount for 10 or more tapes. For an order form, write CILB, 78 Golfwood Heights, Toronto, Ontario M9P 3M2 Canada.

A Reader Writes ...

"In the Fall 1992 issue of *I.V.U.N. News*, I wrote how the use of nasal pillows was helpful during dental treatment. I want to reinforce this, because it has made a major difference in my visits to the dentist. I used to frog breathe and that made dental work a laborious process. Now it is almost a pleasure.

"I have a query for *I.V.U.N. News* readers. How do ventilator users with face masks or nasal pillows handle hospitalizations which require the use of nasogastric tubes? Please advise."

Jack Genskow, 1916 Claremont, Springfield IL 62703, (or e-mail: genskow@uis.edu).

BOOKS

Communication & Swallowing Management of Tracheostomized and Ventilator-Dependent Adults by Karen J. Dikeman, and Marta S. Kazandjian, Singular Publishing, ©1995, is a superbly clear and comprehensive book that should become the classic text on this subject. The co-authors are speech pathologists at Silvercrest Extended Care Facility in Jamaica, New York and New York Hospital Medical Center Queens. Well-organized with references, resources, and a good glossary, the book includes airway management techniques, trach tubes, the spectrum of mechanical ventilation methods, communication options, swallowing and dysphagia, and case studies. It is available from Singular Publishing Group, Inc., for \$57.50 plus \$6 shipping and handling. Call 800/521-8545.

Medically Fragile and Technology Dependent Children: Care in the Community, published by Ken-Crest Services, contains the proceedings from a national conference held March 1995 in Philadelphia. Cost is \$20 postpaid from Ken-Crest Services, One Plymouth Meeting, Suite 200, Plymouth PA 19462 (610/825-9360, e-mail: Centers@libertynet.org).

Noninvasive Respiratory Support, edited by A.K. Simonds, Chapman & Hall, ©1996, is another text for pulmonary health professionals. Simonds is Consultant in Respiratory Medicine at Royal Brompton Hospital in London, and the book is primarily for British practitioners. Although not as comprehensive as John R. Bach's *Pulmonary Rehabilitation*, the Simonds book is certainly a welcome addition to the medical literature about noninvasive ventilation. The paperbound edition is available from Chapman & Hall for \$36.95 plus \$8.50 shipping and handling. Call 800/842-3636 to order.

I.V.U.N. BIBLIOGRAPHY*

Dolmage TE, Eisenberg HA, Davis LL, Goldstein RS. Chest wall oscillation at 1 Hz reduces spontaneous ventilation in healthy subjects during sleep. *Chest* 1996; 110:128-135

Moss AH, Oppenheimer EA, Casey P, Cazzoli PA, Roos RP, Stocking CB, Stiegler M. Patients with amyotrophic lateral sclerosis receiving long-term mechanical ventilation. *Chest* 1996; 110:249-255

Gay PC, Hubmayr RD, Stroetz RW. Efficacy of nocturnal nasal ventilation in stable, severe chronic obstructive pulmonary disease during a 30month controlled trial. *Mayo Clin Proc* 1996; 71: 533-542

Sevick MA, Kamlet MS, Hoffman LA, Rawson I. Economic cost of home-based care for ventilator-assisted individuals. *Chest* 1996; 109: 1597-1606

*Recent professional articles of interest to *I.V.U.N. News* readers, arranged in order of most current publication date.

The month your subscription is due is above your name on the label. Renewal notices are sent to serve as a reminder.

PEOPLE IN THE NEWS ...

CONGRATULATIONS TO GRETHE NYHOLM, RNP, on receiving the Florence Nightingale Prize from University Hospital. Selected from more than 1,500 nurses, Nyholm directs the Center for Home Ventilation at the hospital. She has co-authored a study of home ventilation in Denmark, and her observations on the American form of home ventilation appeared in the Spring 1996 issue of *I.V.U.N. News*. Bravo!

RICHARD DAGGETT, ventilator user and president of Polio Survivors Association in Downey, California, was instrumental in the filming of a public television documentary about Rancho Los Amigos Medical Center which aired this summer. Daggett's persistence — more than five years — finally brought Huell Howser, who filmed and produced it for KCET, Southern California's PBS station, to Rancho. The first half of the hour-long episode, with Daggett as tour guide, shows Rancho during its polio days, iron lungs and all. The second segment looks at Rancho today, its current focus on SCI and head injuries, and its unique status as the only area rehabilitation hospital providing services to indigent patients. A copy of the video, "Visiting ... with Huell Howser: Rancho Los Amigos Medical Center," can be obtained for \$19.95, plus \$6 shipping and handling (and tax for California residents). To order, call VideoFinders at 800/343-4727.

calendar

... 1996 ...

Aequitron Ventilator Network Meeting. NOVEMBER 4, 1996, 7:00-9:15 a.m. San Diego Marriott Hotel, San Diego, California, during the 1996 AARC annual convention. Contact Jan Nelson, Marketing Services Coordinator, Aequitron Medical, Inc., 800/497-4979, ext. 235 or 256.

... 1997 ...

Sixth International Conference on Home Mechanical Ventilation. MARCH 5-7, 1997, Lyon, France. Contact: J.I.V.D., Hopital de la Croix-Rousse, Service de Reanimation et Assistance Respiratoire, 93, Grande Rue de la Croix-Rousse, 69317 Lyon Cedex 4, France (Phone (33) 78 39 08 43, FAX (33) 78 39 58 63, e-mail: 100732.3540@Compuserve.com).

Children Who Are Medically Complex or Technology Dependent: Meeting the Needs of Children and Families. MARCH 5-7, 1997, Sheraton Society Hill Hotel, Philadelphia, Pennsylvania. Contact: Judy Watman, ACSW, LSW, Ken-Crest Services, 5450 Wissahickon Ave., #A 114, Philadelphia PA 19144 (215/844-1842).

SEVENTH INTERNATIONAL
POST-POLIO
AND
**INDEPENDENT
LIVING
CONFERENCE**
ST. LOUIS, MISSOURI, USA

G.I.N.I.'s Seventh International Post-Polio & Independent Living Conference. MAY 28-31, 1997, Marriott Pavilion Downtown, St. Louis MO. Contact: G.I.N.I.,

4207 Lindell Blvd., #110, St. Louis MO 63108-2915
(Phone 314/534-0475, FAX 314/534-5070,
e-mail: gini_intl@msn.com).