

TRAVELLING WITH A VENTILATOR

by Audrey King

Travelling with a ventilator is possible. In spite of the extra baggage you must carry, you too can enjoy the sights and sounds of other wonderful places. All it takes to get started is a dream, a destination, some careful pre-planning, and a sense of adventure.

☛ ***Where do you want to go? Research it and take responsibility.***

Where do you want to go? To the next town or to another state or province? To another country? Research your ideas and consider the options for getting there. Talk to other ventilator users. Lots of people have travelled, even those with a tracheostomy who are full-time ventilator users. Some travel agents specialize in organizing holidays for people with disabilities, but don't expect them to know your particular needs and expectations.

My first trip with a ventilator (which I use at night) was to Barbados. This was in 1966, long before workers worried about their backs and years before policies and procedures for handling people with disabilities were written. In those days a handsome pilot literally lifted you from your wheelchair and carried you up the gangway. That first trip was amazing. The soft tropical air, warm turquoise sea, local people, and relaxed way of life just whetted my appetite for more. I was hooked on travel, in spite of a wheelchair, ventilator, extra luggage, and personal support needs. The world was mine, just waiting to be explored.

On that first trip I learned the importance of research and pre-planning. In Barbados the electrical cycle was 50 rather than 60 and the ventilator would not work properly. For a few anxious hours it seemed I was doomed to return home. Fortunately, a retired family friend loaned the

**From a talk presented during "Exploring Breathing Support Options," April 23-24, 1996, sponsored by Citizens for Independence in Living & Breathing (CILB) of Toronto.*

generator from his illicit moonshine operation and I was able to stay as planned.

☛ ***Check the local electricity before you go: the voltage, the amps, the watts, the cycles, the wall outlets, etc.***

I have travelled to many countries since that first Barbados trip — England, Scotland, Wales, Majorca, Sweden, Germany, Austria, the Netherlands, and all throughout Canada and the United States. I've roughed it in ancient cottages with old-fashioned wiring, travelled on narrow-gauge steam trains, and explored damp, dripping mines deep in the Welsh mountains. I've bunked on a narrow bench in a narrowboat on ancient British canals, camped in the woods, and silently sailed awestruck for a week on the deck of a hundred-year-old, two-masted schooner in the Netherlands.

As you might expect, many trips have required some creative problem-solving, such as extra-long extension cords connected together through the trees at campsites, and multiple books wedged alternatively under each hip to raise from floor to wheelchair height.

☛ ***Be adaptable and creative in solving problems.***

☛ ***Know the local resources.***

In London, St. Thomas' Hospital generously loaned me a comparable British ventilator so I was able to avoid the different electricity problem.

Continued on page 2

Inside This Issue ...

Living with Spinal Muscular Atrophy	5
"Jack" Emerson and the Iron Lung	7
Web Sites	8

My friends and I spent a week's vacation on a British narrowboat (with no electricity) by putting a gas generator at the back of the boat and by running an extension cord along the 70-ft. side of the boat and in through the tiny window where I slept. Can you imagine opening your eyes to a glorious dawn, moored at the foot of a peaceful field in the middle of nowhere, face to face with fifty silent cows, all collectively chewing their cud while contemplating the source of this noisy intrusion? That was a week to remember.

☼ **Take or have access to an alternate power source, such as a battery.**

Travel is exciting and rewarding, but always be prepared for the unexpected. Electricity may not be reliable, particularly in less developed regions. In Majorca, for example, I operated the ventilator from battery because of frequent blackouts. In the Netherlands, when sailing on the 100-year-old schooner, electricity was not available at night, even though I had carefully written in advance and was assured there would be no problem. Fortunately the crew adapted their wiring and set me up with their emergency generator for use during the night.

☼ **Have a backup ventilator.**

☼ **Never be separated from your ventilator.**

Once, when returning to England from Majorca, the airline mistakenly sent both my wheelchair and ventilator to Zurich. The ground crew panicked, but I was calm because I had a backup ventilator and also knew the local resources, should help be required. On another occasion, my suitcase was stolen at Vancouver International Airport. Since then, I've always insisted my equipment accompany me at all times.

Canadian Audrey King is a respiratory polio survivor who frogbreathes intermittently during the day. Her vital capacity is 750ml. She uses a PLV-100 ventilator with a Respironics nasal mask at night.

☼ **Take a letter stating that essential equipment must stay with you and attesting to your expertise in handling it.**

☼ **Take a personalized travel kit.**

The more you travel the more skillful you will become at planning and preparing. You'll find yourself taking more and more bits and pieces for all kinds of possibilities. You'll probably assemble a travel kit of generally useful things, such as small tools, extension cords, a surge-protected power bar, and a "cheater" plug which enables you to put a three-pronged plug into a two-hole outlet. (Many cottages and old buildings have non-grounded two-holed outlets. Cheater plugs are not approved in Canada, but can be purchased in the United States.) Adapters are needed for electrical outlets in other countries. A transformer is needed to convert the electricity of another country to that required by your ventilator. You might also include gaffer or masking tape, string, and safety pins.

☼ **Take extra supplies.**

☼ **Consult with electrical experts.**

Be sure to take extra supplies in case something gets damaged or lost. Always consult with an electrical expert before you go in order to ensure you have the right conversion equipment.

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

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

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☼ **Protect your equipment.**

You'll become more efficient at packing and packaging your equipment. A modified luggage dolly with bungie cords is useful for trundling heavy equipment through airports and over long distances. I've designed a heavy canvas carrying case with sufficient space and pockets on the sides to pack soft protective towels, pads, and clothes around the ventilator. The case is easy to zip open for airport inspections and for use during transit.

☼ **Know airline/bus/train and customs policies and procedures.**

☼ **Allow extra time.**

Security personnel at airports are justifiably nervous about equipment they have never seen. Only once was I nearly refused clearance. The situation was understandable enough, as the passenger just ahead of me was apprehended for trying to board with a chain saw in his luggage. It helps if you are familiar with airport procedures and policies.

Allow enough time for officials to be satisfied and comfortable. An extra half hour, at least is required for pre-boarding. And remember to allow time for last-minute personal needs, like using the washroom.

☼ **Know your ventilator settings and operation.**

Know your ventilator settings and how to do basic setup and problem-solving. Ventilator connections can become loose, circuit breakers can pop out, and knobs can get changed with all the equipment handling.

☼ **Know your travelling companions.**

A successful trip will ultimately depend on the compatibility between yourself and those who travel with you. Whether it's family, friends, or paid assistants, you must feel comfortable and secure with each other before you start out. If possible, do a 48-hour dry run together before you leave. Spending continuous time together can be tough for even the best of friends.

Unfamiliar environments, luggage handling, and dealing with unexpected situations over which you have little control cause stress and fatigue. You can't be as independent as you are at home. Some people prefer to travel with an organized group where stress is lessened because luggage is handled, and route, accommodations, and procedures are checked out by others before the trip begins.

☼ **Know yourself.**

What kind of trip do you want? One that is energetic and full of adventure or one that takes just getting there and relaxing? What kind of person are you? An optimist with a sense of adventure? A person with reasonable energy? Can you roll with the punches? Are you a planner — a level-headed, flexible, responsible kind of person who can solve problems in a practical way as they occur? Can you adjust to circumstances with humor and an ability to tell a good tale afterward? If the answers are YES, then go for it!

It could be a trip to the next town or to the other side of the world, but the sights and sounds, the photos, and long-lasting memories of being in another place will stay with you through even the bleakest winter. It all begins with a dream and a plan.

ADDRESS: Audrey King, Client Advocate, Bloorview MacMillan Centre, 350 Ramsey Rd., Toronto, Ontario M4G 1R8 Canada.

TRAVEL RESOURCES:

Access for Travel, Consultation, & Training.

Carol Lee Power, 1429 10th St., W., Kirkland WA 98033. 206/828-4220.

Breathin' Easy: A guide for travelers with pulmonary disabilities. Listing of 3,000 oxygen providers and traveling tips. Available from Breathin' Easy Publications for \$19.60 postpaid, 3130 Crow Canyon Rd., Suite D, San Ramon CA 94583. 888/OXYGEN-0.

Flying Wheels Travel, Inc. Barbara Jacobson, P.O. Box 382, Owatonna MN 55060. 800/535-6790.

Living and Traveling with Oxygen by Jean Gomez. 1997. Spiralbound 120 pages. Available for \$19.95 postpaid from Jean Gomez, 9304 Oakland Ave., NE, Albuquerque NM 87122.

Society for the Advancement of Travel for the Handicapped (SATH). 212/447-7284.

Travelin' Talk, network, newsletter, directory. Rick Crowder, 130 Hillcrest Plaza, #102, P.O. Box 3534, Clarksville TN 37043-3534. 615/552-6670. Fax 615/552-1182.

Wheelchair Getaways, Inc. P.O. Box 93501, Albuquerque NM 87199. 800/642-2042.

How Will They Know If I'm Dead? TRANSCENDING DISABILITY AND TERMINAL ILLNESS

by Robert C. Horn III, PhD

REVIEWED BY JUDITH R. FISCHER

I.V.U.N. News readers will remember the eloquent editorial by Dr. Horn in the Fall 1996 issue. Dr. Horn's book, with its most attention-getting title, is no less eloquent. This positive and often funny volume is divided into three parts: Living Life, Choosing Life, and Affirming Life. Horn discusses his decisions to proceed with a tracheostomy and g-tube, offers practical advice for living everyday with a trach and ventilator, and sings songs of praise and gratitude for his family and friends. Dr. Horn, Professor Emeritus of political science at California State University, Northridge, appeared at a recent book-signing event on campus, and his book sold out all 300 copies available.

For many people with ALS, the decision about trachs and ventilators can be an agonizing and complex one. For Horn, however, it was simple. He writes, "For me, the pros of living so overwhelmed the cons of having to do so permanently hooked to a ventilator that it was absolutely no contest. My dependence was already total. I was paralyzed, could barely speak above a whisper, and was having greater problems eating and even breathing. What did I have to lose? I might even gain! ... Sure, I would be kept alive artificially by a ventilator but my life would be real, not artificial."

In recounting the challenges of and obstacles to living with a ventilator, Horn describes one particular episode when his van broke down and he was rescued by a California Highway Patrol officer and an airport shuttle company as ... "the struggle between the dark forces of bureaucracy and the forces of light, humanity." He recalls living through the Northridge earthquake in 1994 when by some stroke of luck or fate he was scheduled to go to the hospital — the hospital had electricity and his home did not. He later told a reporter for the Los Angeles *Times* that he went to the hospital because "I couldn't deal with the cleanup."

In conclusion, Gordon Dowds, MD, Horn's pulmonary physician, contributed this: "My perspective is that we all start out living in a very

small circle. Wrapped in a blanket, covered in a crib, we begin. The expansion of our circle is easy — we explode as young adults. It is the contraction that is hard. We all some day must contract. It may be from ... a crippling disease. A sudden catastrophe such as ALS or a stroke. The measure of the man is how rich we make the small sphere that we will one day find ourselves enclosed within." Bob Horn's small sphere is very rich indeed.

How Will They Know If I'm Dead? Transcending Disability and Terminal Illness by Dr. Robert C. Horn, (1997, 120 pages, paperback) is available for \$12.95 plus \$4.95 shipping and handling through St. Lucie Press, 100 E. Linton Blvd., Suite 403B, Delray Beach FL 33843. Phone 561/274-9906. FAX 561/274-9927.

VENTILATOR USER DOCUMENTARY WINS OSCAR

"Breathing Lessons," about the life of ventilator user Mark O'Brien, was awarded an Oscar for Best Documentary-Short Subject during the Academy Awards ceremony on March 24. O'Brien is a poet and journalist who uses an iron lung because of polio. He writes for the Pacific News Service and National Public Radio; his collection of poetry is entitled "Breathing." O'Brien states, "The two mythologies of disabled people break down to: one — we can't do anything, or two — we can do everything. But the truth is we're just human."

Produced by Jessica Yu, the 35-minute video is available for purchase for \$195, or \$50 per one day rental. Order no. LL-180 from Fanlight Productions, Inc., 47 Halifax St., Boston MA 02130. 800/937-4113.

LIVING WITH SPINAL MUSCULAR ATROPHY

by Jacqui Taptto



Our daughter Mandy was diagnosed with spinal muscular atrophy, type I, on February 17, 1995, at the age of 8 months. Her disease was so rapidly progressive that by early March we had to decide whether or not to ventilate her. The decision came easily to us because we measure life by love given and received, not by physical abilities. Mandy has used trach positive pressure ventilation with a Puritan Bennett 2800 since then.

We came home at first with daily visits from a hospice care nurse, but soon realized that, with mechanical ventilation, Mandy's prognosis was more positive than we had recognized (we signed off on hospice care after about six months). The Family Leave Act had just gone into effect when we came home from the hospital and my husband Neal had the opportunity to stay home to take care of Mandy. I was the one who kept on working, although he made more money than I did. After Neal had stayed at home for one year, he had to choose between continuing to stay at home and paying elevated insurance premiums or returning to work and maintaining our insurance at a more affordable rate. Neal returned to work, but he loved staying at home with Mandy and had no regrets.

Currently, nursing visits last only about 15-20 minutes every two to three weeks. A respiratory therapist visits once a week, and our pediatrician makes house calls as needed. Neal and I are Mandy's primary and sole caregivers. We learned

trach and ventilator care over time with the help of respiratory therapists who were patient and willing to teach us proper care and procedures.

Mandy's schedule is very demanding. She is fed meals through a g-tube four times per day, with frequent juice feedings in between. Chest percussion is performed every two hours and nebulizer treatments are provided three times per day. Mandy cannot speak actual words yet, and communicates mainly through facial expressions and vocalizing sounds.

Since Mandy's diagnosis, we have been active in advocating for rights for people with disabilities. We received a letter from President Clinton acknowledging the need for increased funding for genetic diseases and have been published in several publications ranging from *Time* magazine to the "Dear Abby" column. Neal was chosen as one of six best dads of the year last Father's Day and was featured on the Oprah site on America Online.

We wish other people could see Mandy through our eyes — see her smile, her curiosity, her happiness — instead of seeing her as a ventilator-assisted child. When people look at her in a way that I disapprove of, I tell Mandy that they are looking at her because she is so beautiful, which is the way she should be seen. We believe that ventilator users have yet to be accepted by society and it is only by speaking out and having a strong voice that we will be heard.

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DEADLINE ...

for submission of articles, stories,
information, etc. for the Fall 1997 issue
of *I.V.U.N. News* is
September 15, 1997.

Please mail, FAX, or e-mail:

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

I.V.U.N. DIRECTORY UPDATE

Long-time ventilator users and health professionals who are experts about and advocates for home mechanical ventilation are listed. This update is a companion to the *Directory* published in *I.V.U.N. News*, Fall 1996, Vol. 10, No. 2. Corrections and changes are underlined. Send additions, deletions, and corrections to: I.V.U.N., 4207 Lindell Blvd., #110, Saint 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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562/494-5839 562/494-5675 FAX

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630/963-6390 630/963-5947 FAX

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VENTILATOR SESSIONS AT G.I.N.I. CONFERENCE

Of interest to ventilator users are sessions planned for the Sixth International Post-Polio & Independent Living Conference, May 29-31, at the St. Louis Marriott Pavilion Downtown. On Friday afternoon, May 29, there will be a forum discussing ventilator use around the world, the effects of aging on ventilator equipment choices, and the latest in facemasks. On Saturday morning, May 30, workshops will be offered on ventilator and bi-level pressure devices; assisted cough-

ing — benefits and techniques; frogbreathing; and medical concerns of living longterm with a ventilator. Transcripts of the sessions will appear in future editions of *I.V.U.N. News*.

For registration information, 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

JOHN H. EMERSON AND THE IRON LUNG

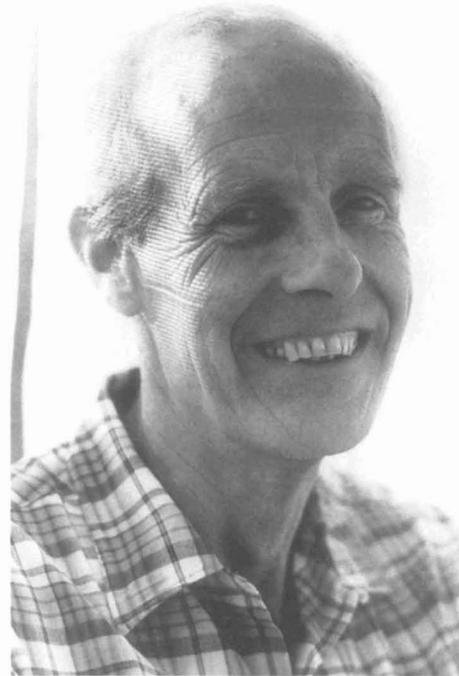
by Judith Raymond Fischer

John Haven Emerson died of cancer on February 4, 1997, at the age of 90. He designed the most widely used iron lung which saved the lives of countless polio survivors during the epidemics of the 1950s. "Jack" Emerson never graduated from high school and was a self-taught inventor. Founder and President of J.H. Emerson Co. in Cambridge, Massachusetts, Emerson's company developed other breathing devices for hospitals, including resuscitators for drowning and smoke inhalation victims, hyperbaric oxygen chambers for burns, breathing devices for scuba diving, and revived the device enabling people who use ventilators to generate a cough and clear secretions.

Emerson was the first non-physician awarded a medal by the American Thoracic Society for outstanding contributions to respiratory medicine. He also received honorary membership in the American Association for Respiratory Therapy and the American Association of Critical Care Nurses. In his later years, Jack Emerson continued to help tend the company's exhibit booth at medical conferences, and was a warm and familiar face.

According to Emerson's commentary in a booklet chronicling his company's 50th anniversary in 1978, the earliest body-enclosing mechanical respirator that produced ventilation by pressure changes within a chamber was patented in the United States in 1864, and, in 1882, Alexander Graham Bell designed a "vacuum jacket" driven by bellows. The availability of electricity aided the further development of the respirator. In 1926, Harvard University Medical School's Philip Drinker, an industrial engineer, and Louis Shaw, a physiologist, designed a

machine for "prolonged administration of artificial respiration." It had its first clinical application on a child with bulbar polio in 1928 at the



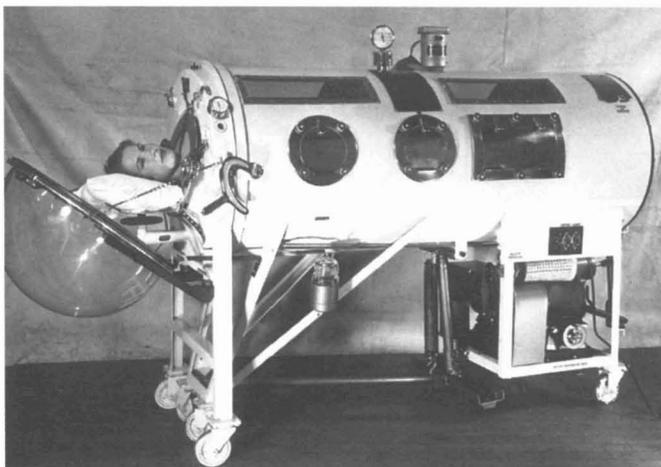
Children's Hospital of Boston. Although cumbersome and inconvenient, it did save lives. New York Consolidated Gas Company provided funding for the first machines to study their use for resuscitation of people with gas poisoning and electric

shock, but it became clear that any new technology for prolonged mechanical ventilation would have wider application in the management of paralytic conditions, especially poliomyelitis.

In 1931, a severe epidemic heightened the demand for these mechanical respirators, which the press dubbed the "iron lung." However, the design made it difficult to provide complete nursing care and to change the patient's position. Emerson built a simplified respirator to meet both the needs and the demand. He developed a respirator which cost less than half as much as the others, but also made the machine more practical and convenient. His improvements included a respiration rate variable over a wide range; quieter operation; quick insertion and removal of the patient; and if the electricity failed, it could be pumped by hand. In a short time, Emerson's design completely replaced the Drinker and Shaw model. (Emerson's first iron lung is preserved at The Smithsonian Institution as the prototype of respirators constructed since 1931 in the United States and Europe.)

Later of course, the iron lung was superseded by less cumbersome negative pressure body ventilators, positive pressure ventilation via

Continued on page 8



Camps for Ventilator-Assisted Children

1997

May 31-June 6, Trail's Edge Camp, Michigan. Contact Mary Dekeon, RRT, C.S. Mott Children's Hospital, University of Michigan, 200 E. Hospital Dr., F3064, Box 0208, Ann Arbor MI 48109. 313/763-2420.

June 9-13, CHAMP Camp, Recreation Unlimited, Ashley OH. Contact David Carter, RRT, CHAMP Camp, P.O. Box 40407, Indianapolis IN 46246-0407. 317/787-4555.

August 18-22, Camp Inspiration, Rocky Mountain Village, Empire CO. Contact Monte Leidholm, RRT, The Children's Hospital, 1056 E. 19th Ave., Denver CO 80218. 303/837-2502.

August 28-August 31, SKIP Camp, Seashore United Methodist Assembly, Biloxi MS. Contact Judy Abney, SKIP of Louisiana, 118 Ned Ave., Slidell LA 70460. 504/649-0882.

1998

April, Ventilator-Assisted Children's Center (VACC) Camp, Miami FL. Application due 12/31/97. Contact Cathy Klein, VACC, 3200 S.W. 60th Ct., Suite 203, Miami FL 33155-4076. 305/662-VACC.

WEB SITES OF INTEREST TO I.V.U.N. NEWS READERS

American Academy of Pediatrics
<http://www.pediatrics.org>

American Association for Respiratory Care (AARC)
<http://www.aarc.org>

American Lung Association
<http://www.lungusa.com>

Amyotrophic Lateral Sclerosis Association
<http://www.alsa.org/home>

Families of Spinal Muscular Atrophy
<http://www.abacus96.com/fsma>

FDA Medical Device Reporting Information
<http://www.fda.gov>

Guillain Barre Syndrome Foundation International
<http://www.webmast.com/gbs/index.html>

HHS Health Information
<http://www.healthfinder.gov>

Metabolic Information Network —
Metabolic Myopathies
<http://www.familyvillage.wisc.edu>

MedWeb
<http://www.cc.emory.edu/WHSC/medweb.disabled.html>

Myasthenia Gravis Foundation
<http://www.med.unc.edu.mgfa>

Neuromuscular Disease Center, Washington University,
St. Louis MO
<http://www.neuro.wustl.edu/neuromuscular/>

Neuroscience Web Search
<http://www.acsiom.org/nsr/neuro.html>

NIH Clinical Center Research Studies
<http://www.cc.nih.gov>

For Parents of Boys with Duchenne Muscular Dystrophy
<http://www.ceg.co.za.megaweb/md/dmdtxt.html>

Parent Project for Muscular Dystrophy Research, Inc.
<http://www.parentdmd.org>

Passy-Muir, Inc.
<http://www.acclaimedmedia.com/passy-muir>

Pedbase
<http://www.icondata.com/health/oedbase>

PediaNet
<http://www.pedinet.com>

Ventilator users
<http://www.eskimo.com/jlubin/disabled/vent/index.html>

Wellness Web
<http://www.wellweb.com>

Words+: Augmentative and Alternative Communication
<http://www.words-plus.com>

JOHN H. EMERSON Continued from page 7

tracheostomy, nasal or facial masks, and bi-level pressure support systems. However, for respiratory polio survivors of the '50s epidemics, the iron lung symbolizes life and breath, and although not many today still use their "tanks," they all value its role — and Jack Emerson's engineering — in saving their lives.

SOURCES:

Emerson, JH. *The Evolution of Iron Lungs*. The J.H. Emerson Company, Cambridge, Massachusetts, 1978.

Drinker P, McKhann CF. The use of a new apparatus for the prolonged administration of artificial respiration. *JAMA* 1929; 92:1658-1600

Drinker PA, McKhann CF. The iron lung: first practical means of respiratory support. *JAMA* 1986; 255: 1476-1480



IN MEMORIAM

D. Armin Fischer, MD

Dr. D. Armin Fischer died January 23, 1997, at the age of 71 of the complications of Alzheimer's disease. As Chief of the Chest Medicine Service at Rancho Los Amigos Medical Center in Downey, California, until his retirement in 1989, Dr. Fischer was a favorite physician of polio survivors and an ardent advocate of living at home with mechanical ventilation. He wrote several articles on the pulmonary problems of polio survivors and was especially interested in sleep-disordered breathing and underventilation in polio survivors. He wrote the pulmonary sections of the *Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors*, published by G.I.N.I. in 1984. His wife, Judith Raymond Fischer, is editor of *I.V.U.N. News*. Contributions in his memory may be made to I.V.U.N., in care of G.I.N.I.

**SSI BENEFIT CHANGES
FOR CHILDREN WITH DISABILITIES**

The new definition of disability in the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 requires a physical or mental condition(s) that can be medically proven and which result(s) in marked and severe functional limitations. The new law eliminates individual functional assessments. The implementing regulations require that impairment(s) must meet, medically equal, or functionally equal the requirements of a listing. The rules include more guidance to ensure careful evaluation of children with physical impairments as well as impairments that are chronic. The new regulation is effective for new claims and claims not finally adjudicated as of 22 August 1996.

Some provisions require a continuing disability review of a case every three years if the child's impairment(s) is/are likely to improve. At a continuing disability review, a child's representative payee must show evidence that a child is and has been receiving treatment to the extent "medically necessary and available" for the disabling condition. A review using the adult standard for disability must be conducted for children when they reach age 18. No benefits will be stopped before July 1, 1997.

**LIVING WITH ALS
MANUALS REVISED**

The ALS Association revised their excellent series of manuals — *Living with ALS* — to reflect advancements in the care of people with ALS due to the exciting pharmacologic breakthroughs and rapidly expanding information and research in ALS. Designed to inform and educate people about ALS in a comprehensive and easily understood format, the manuals are titled: *What's It All About?* (\$15); *Coping with Change* (\$15); *Managing Your Symptoms and Treatment* (\$20); *Functioning When Your Mobility Is Affected* (\$20); *Adjusting to Swallowing and Speaking Difficulties* (\$15); and *Adapting to Breathing Changes* (\$25).

The manuals are free to persons with ALS and their families, except for shipping costs of \$3 per manual. Order forms can be obtained from The ALS Association, 21021 Ventura Blvd., Suite 321, Woodland Hills, CA 91364. Phone 818/340-7500 or FAX 818/340-2060.

HOME MECHANICAL VENTILATION CONFERENCE

Göteborg, Sweden ♦ October 1996

Notes by Grethe Nyholm, RNP
Center for Home Ventilation, Copenhagen

Sponsored by Breas, manufacturer of a new, small, Swedish home ventilator, this regional conference drew approximately 40 doctors, nurses, and physiotherapists from Denmark, Norway, and Sweden.

➔ In Sweden, the ratio for people with neuromuscular disorders is 84:100,000. In Danderyd Hospital in Sweden, there are specialists in adapted tracheostomy tubes, most of them made of silver or plastic. Many of these tubes have windows and special custom-made inner tubes to fit the ventilator. 61 people live at home with these special tubes.

➔ In 1996, 20 people in Sweden began ventilator use: 10 using BiPAP® systems, five using PLVs, and five using the new Breas ventilator. The average age was 60 years.

➔ In Denmark, about 300 people are living at home with a ventilator. The number is increasing rapidly. More and more people are ventilated

with custom-made nasal masks which are more convenient, effective, and cheaper than the standard masks.

➔ Norway and Sweden are large countries and it is difficult to make one or two centres for home mechanical ventilation as in Denmark with one in Copenhagen and one in Aarhus.

➔ An interesting ethical aspect of ventilator use in Nordic countries is that ventilators cannot be turned off or unplugged, even if the patient wants to do that. When a patient is recommended to begin ventilator use, the patient's autonomy must be considered. The patient must decide about the ventilator. Will the patient have a better quality of life? Every patient will have the same rights and opportunity for the best treatment. The subject is discussed very much in Denmark.

➔ The next meeting is April 18-19, 1997, in Göteborg.

SIXTH INTERNATIONAL CONFERENCE ON HOME MECHANICAL VENTILATION

Lyon, France ♦ March 1997

For information on obtaining copies of the *Proceedings*, contact JIVD, Hôpital de la Croix-Rousse, Service de Reanimation Medicale et d'Assistance Respiratoire, 93, Grande-Rue de la Croix-Rousse, 69317 Lyon Cedex 04 France. Phone 33 (0)4 78 39 08 43 or FAX 33 (0)4 78 39 58 63 or E-mail: 100732.3540@Compuserve.com

CANINE COMPANIONS FOR INDEPENDENCE AND VENTILATOR USERS

Steven Linder, MD, Palo Alto VA Medical Center, likes to tell the tale of Merrill Burgardt and his dog Heidi, a Canine Companion. Disabled by a bullet to his neck which left him paralyzed below the shoulders and a ventilator user, Burgardt had pneumonia and was awaiting admission to the VA hospital in La Jolla. He had urged his attendant to go out for a break, but soon felt his lungs filling with fluids. Heidi sensed his anxiety and Burgardt was certain that if he could get Heidi to lie down on his chest that he would be able to cough. He signaled to Heidi, pretending to have a treat in his hand, to stand over him, and then commanded,

"Down." The dog immediately plopped on Burgardt's chest and helped generate a cough to clear his lungs. After he recovered, Burgardt taught Heidi a new command, "Cough."

Canine Companions for Independence (CCI) trains dogs to assist people with disabilities other than blindness and has five regional facilities throughout the United States.

For more information contact CCI, P.O. Box 446, 2965 Dutton Avenue, Santa Rosa CA 95402-0446. Phone 707/577-1700; TDD 707/577-1756. Visit their Web site at <http://www.caninecompanions.org/>

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Potpourri



NELLCOR
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NELLCOR PURITAN BENNETT, INC. acquired Aequitron Medical, Inc. in December 1996.

Aequitron is now part of Nellcor Puritan Bennett's Alternate Care Division. Aequitron's products will continue to be manufactured in Minnesota and LP ventilator users can continue to receive the customer and technical support to which they have been accustomed.

LIVING AND TRAVELING WITH OXYGEN by Jean Gomez (1996, 107 pages) also includes information on traveling with a ventilator, many resources, and helpful tips about electricity converters and adapters. Available for \$19.95 postpaid from Jean, 9304 Oakland Ave., NE, Albuquerque NM 87122. 505/822-0862.

CONGRATULATIONS TO TERI NIKOLAI WILSON, RRT, RPFT, upon receiving the LIFECARE Fellowship on Mechanical Ventilation during AARC's annual meeting in November 1996. The fellowship is designed to foster projects on mechanical ventilation, especially outside the intensive care unit. Wilson's study of the safety and cost-effectiveness of ventilator circuit tubing changes appeared in *I.V.U.N. News*, Fall 1995.

POMPE'S DISEASE may have a potential drug treatment. A Dutch biotech firm, Pharming, has created a line of transgenic rabbits that secrete in their milk the enzyme that is dysfunctional in people

with Pompe's disease. The disease prevents the conversion of glycogen in muscles to glucose, leading to muscle damage and breathing problems. Researchers have theorized that injections of a functional version of the enzyme could prevent muscle deterioration, a theory that, before the rabbits, was untested in humans due to limited supplies of the enzyme. The milking facility, expected to be ready in two years, could produce enough of the enzyme to satisfy worldwide demand. The USDA granted "orphan drug" status to the enzyme in September 1996. Source: *Science*, 1996; 274: 1617.

POLYSOMNOGRAPHY: An Overview of Testing for Sleep Disorders from ECRI's Health Technology Assessment Information Service rates polysomnography (PSG) for its appropriateness as a diagnostic tool to a primary diagnosis for each specific sleep disorder. The extensive 343-page report finds that, while PSG is sometimes an effective and necessary tool for the diagnosis of many sleep disorders, PSG is being used inappropriately to diagnose other sleeping disorders that could be diagnosed more cost-effectively with ambulatory testing procedures that are less intrusive and less expensive. Members of ECRI's service may order the report at a special rate from ECRI, 5200 Butler Pike, Plymouth Meeting PA 19462-1298. Phone 610/825-6000 or FAX 610/834-1275.