

LONGTERM HOME VENTILATION AND LIVING INDEPENDENTLY: THE USERS' PERSPECTIVES

*Excerpts from a panel of ventilator users during
the Fifth International Conference on Pulmonary Rehabilitation and Home Ventilation,
Denver, Colorado, March 14, 1995*

RICHIE WHITCOMB *Richie became a ventilator user after he was injured in an automobile accident at age 4^{1/2}. He has two LP6s; one on his power chair and the other at his bedside.*

My name is Richie Whitcomb. I am 9 years old. I have used a ventilator for five years. I am a third grade student at an elementary school in Arvada, Colorado. I have a full-time aide named Teri. She



The Whitcomb Family

acts as my hands. She turns on my computer, gets my books and lap tray, and changes my mouthstick. She also takes care of all my medical needs.

I have a lot of friends at school. They don't care that I use a ventilator. I have learned it is the adults who are afraid of me. This is a big problem in school. Everyone is worried about taking care of me and

whose responsibility it is. The adults say it is not that they do not like me. They say it is about legal issues.

My teacher says that the ventilator causes a lot of noise in the classroom. She says the other kids have to adjust their listening to hear communication in the classroom. She also says that because I

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AMY KAMP *Several birth defects plus respiratory complications from scoliosis led to a tracheostomy and ventilator when Amy was 14. "When I was trached, noninvasive ventilation was not an option, but this conference has enabled me to see that noninvasive ventilation might be an option for me now."*

I am 23 years old, a graduate student at Indiana University in Bloomington, pursuing a Master of Fine Arts in graphic design. I am also an associate instructor there teaching graphic design. I have had a trach for almost ten years now and used an LP6 ventilator for almost that long. I have learned from my experience that having a trach is not the end of the world — that a person can do anything that he or she did before a tracheostomy and ventilator OR that everything can be adapted so a person can do it. Attending graduate school was a chance not only to further my education but to prove that I could take care of myself and create a whole new support system away from my family. Maybe I can't jump into a car and go to Mardi Gras for the weekend with my friends, because some logistics have to be worked out, but working out those logistics makes me feel more independent.

In some respects, I think receiving a trach was the best thing that ever happened to me, because it made it easier to breathe. I was able to get enough sleep at night, and got over infections much quicker. I have learned that you cannot always do what everyone tells you to do, such as changing the ventilator circuits every other day. I just don't do it; if I did I would probably spend 16 hours per day taking care of myself and my equip-

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have to have an aide talk to me that it causes more noise in the room. My aide and I always whisper, and I sit away from all the other kids in the back of the room by the coat rack. My teacher also thinks that having a ventilator child in the classroom is a big risk to everyone else. She feels that I am limiting what she can do as an educator.

*I was staying outside with
the wind blowing around me
and the sun shining on me
I like the sun
because it warms my face
I like the wind
because it blows in my face
My face feels what my hands cannot
My breath is like the wind
It drives my chair and it carries me there
The wind is like my legs*

—Richie Whitcomb

I know she gets frustrated waiting for me to speak. I get frustrated because I know an answer, but cannot talk fast enough or loud enough, so someone else answers before me. I get behind in writing and math because someone must write for me.

I hope to be getting a voice command computer to help me write faster. There are 2,000 words you have to say and have the computer recognize. You can imagine how long this might take me because each sound has to be the same and I have to wait for the ventilator to cycle each word. What might take most people two or three hours will take me 20-30 hours.

Sometimes I have so much to say and end up not saying much because it takes me so long to talk. I feel like people get tired of waiting for my words to come out. I have learned to be very tolerant and patient. I wish I could get off this ventilator, but I am afraid because I think I might not be able to breathe one day. I am thankful I have the ventilator to keep me alive.

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ment and the other 8 hours sleeping. I think a person needs to find a happy medium between what people tell you you have to do and what you feel happy and healthy doing in terms of your health. The most important thing I want to stress is that you should not let your health consume your life. You are the only person who knows what is right for you — no one else does.



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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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SOME STATE BUDGETS CUT ATTENDANT CARE

New York ventilator users who live at home with attendant care face extreme budget cuts, according to Ira Holland, President of Concepts of Independence, Inc. Concepts is a unique New York City-based, Medicaid-funded, home attendant care program with 400 clients and 700 home attendants, that saves New York Medicaid nearly \$10 million annually.

Under the proposed Medicaid cuts, personal care services would be capped at 100 hours per month. This equals a maximum of 25 hours of home care per week or 3 hours per day. After many meetings with key budget officials, Holland learned that a waiver for the caps would be sought for the "self-directing physically disabled population."

Holland writes, "We are deeply concerned that the very existence of home care is at stake. There would appear to be a tendency to roll back social services to a period when institutionalization was the preferred choice for severely disabled individuals. . . . I am hopeful that our ceaseless efforts to maintain the Concepts program will reflect a need to focus on the necessity for the establishment and broadening of other cost-effective home care programs across the country. Institutionalization is not the solution to the question of cost-containment. If the State will examine the real costs, then reason will prevail. Now is the time to initiate the essential dialogue. . . . I sincerely believe

that they are more interested in the implementation of programs that will cost government less than institutionalizing disabled people."

In California, Richard Daggett, President of the Polio Survivors Association, reports possible cuts for the In-Home Support Services program, but has not heard how much would be slashed.

In Minnesota, Leah Welch, Director of Independence Crossroads, Inc., writes that the proposed state budget will cut 25% of available hours for people who require personal care, except those who use ventilators.

Yet in Illinois, the proposed 1996 budget for Department of Rehabilitation Services (DORS) includes \$9.6 million in funding increases for in-home services for people with disabilities, with more than 17,500 people expected to receive home services. However, in order to maximize federal reimbursement for those services and lessen reliance on the state's general funds, DORS is initiating a tiered-eligibility system. This enables those with incomes lower than the federal poverty level (less than \$614 per month) to enter the program at will. Those with incomes higher than the poverty level are eligible to enter the program as space becomes available. DORS Director Audrey McCrimon assures, "The tiered system will apply only to program administration and is not expected to affect services."

IN MEMORIAM: EDWARD V. ROBERTS

Ed Roberts, ventilator user due to respiratory poliomyelitis, died suddenly March 14, 1995, at the age of 56. President Clinton, in a message from the White House, said, "As an international leader and educator in the independent living and disability rights movements, he fought throughout his life to enable all persons with disabilities to fully participate in mainstream society. Mr. Roberts was truly a pioneer. . . . His vision and ability to bring people together should be an example for all Americans."

In 1962 Roberts was the first person with a severe disability to attend the University of California at Berkeley, even though his "dorm" was the university's infirmary. Roberts and roommate John Hessler (SCI quad), who entered UC-Berkeley in 1963, along with Larry Langdon and Phil Draper became known as "The Rolling Quads." They led the way in obtaining a grant for what is now the Disabled Students Program at UC-Berkeley. They also proved that they could live on their own outside institutions. They established the Center for Independent Living in Berkeley in 1972, which served as the model for other independent living centers across the country as the independent living movement gained momentum.

In 1975 Roberts was appointed head of the State Department of Rehabilitation by California Governor Edmund G. Brown, Jr., and served until 1983. With Judy Heumann and Joan Leon, Roberts cofounded the World Institute on Disability, a think tank on disability issues, in 1983. After receiving an award from the MacArthur Foundation in 1984, Roberts used the money to further fund the Institute.

The Ed Roberts Memorial Scholarship has been established to support Berkeley students with severe disabilities. To make a donation to the scholarship fund, send donations to: Disabled Students Program, UC-Berkeley, 230 Golden Bear Center, Berkeley CA 94720-4250.

CHILDREN AND TEENS AS VENTILATOR USERS

CLARE

by Elizabeth McDonald

Our daughter Clare was born with muscular dystrophy in 1982. Following a severe spinal collapse in 1988 which was arrested by spinal fusion, Clare's resulting scoliosis left her with only 24% lung capacity. Prior to the ventilator, Clare was suffering from under-ventilation when she was sleeping. This caused severe headaches and distress, and was potentially life-threatening.



In 1988, at age 6, Clare was given a Respironics BiPAP® system (paid for by the Muscular Dystrophy Association). Due to her age, doctors were very skeptical about her ability to adapt to using a ventilator. However, after months of persevering, Clare gradually built up her duration of overnight ventilation until eventually she was able to use the machine all night. To our knowledge she was the first child in Scotland to successfully use noninvasive nocturnal ventilation at home. Our physician, Dr. James Paton of Glasgow's Sick Children's Hospital, developed a program for children requiring home ventilation, and Clare's successful use of the ventilator has been due to his expertise.

Clare's quality of life and health have been greatly helped by nocturnal ventilation. The major problem we've experienced over the last few years has been obtaining a supply of masks to fit Clare. Respironics unfortunately stopped making the mask which suited Clare, and we have had great difficulty in finding an alternative. Dr. Paton had sent one of his staff nurses to the CCHS meeting in the United States, and it was she who suggested we contact Joan Headley and the International Ventilator Users Network (I.V.U.N.) in St. Louis. Headley put us in touch with the Respironics European representative who in turn led us to Mr. D.D. Vara, a technician in Glenfield Hospital, Leicester, England. We have been to visit D.D. on two occasions and he has been most helpful and supportive. He ingeniously redesigned and adapted existing equipment to suit Clare's needs. We are currently trying nasal prong venti-

lation which he adapted to fit Clare, and this seems to be the solution.

Clare, now 13, is a very bright, clever girl with a great sense of humour and mischief. She loves animals and spends much of her time looking after her two dogs. She is now in her first year at high school and copes well with her school work. Clare's favorite spot on holiday is Loch Lomond, where she enjoys sailing.

ADDRESS: Clare McDonald, 28 Clydeford Dr., Uddingston, Glasgow G71 7DJ Scotland.

BILL BROWN

"Recently I became aware of I.V.U.N. and am interested in networking with other teens and young adults. Due to an injury at birth, I use a wheelchair and PLV-100 at night. I am 16 and a sophomore in high school, interested in music, sports, and other school-related activities. My address is 384 Old Enfield Rd., Belchertown MA 01007."



MICHELLE

by Ellen Coe

Michelle, an incomplete C1 quadriplegic due to a birth defect, is a fun-loving adventurous 6-year-old who does not let much stop her. Despite several major surgeries to stabilize her spine, Michelle has significant nerve damage and permanent disability. She has used a ventilator since the age of 5 months. When she turned 3, Michelle got her first power wheelchair with a joystick. She has enough arm and hand function and quickly learned how to drive herself.

After Michelle came home, my goal as a parent was to make Michelle's childhood as normal as I could. One of the first challenges we attempted was to go to the mountains; Michelle was a year and a half. Since then, we have expanded our horizons and go camping every summer. We have taken plane trips to California and Florida, and long driving trips to Montana to see friends and

family. This last summer Michelle had her first experience at a camp especially for ventilator



users. Michelle's first goal was to ride a horse. After she did that, she wanted to participate in as many of the other activities that she could fit in. One of her favorite activities is swimming.

Michelle attends kindergarten with a home care nurse. She has two LP6 ventilators; one on

her wheelchair and one set up in the house. On vacations and long trips, we always take both ventilators and an ambu bag.

A supportive family and encouraging friends help make Michelle's life full and enjoyable. These days she doesn't want to be left behind anytime I go out.

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MATT

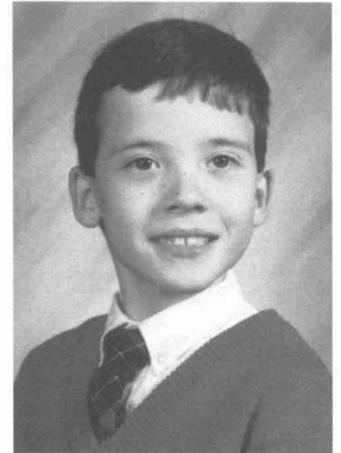
by Nancy Stone

Matthew, our first child, was born in 1986 with congenital central hypoventilation syndrome (CCHS), also known as Ondine's curse. CCHS is characterized by the lack of response to CO₂ buildup, leading to hypoventilation, usually during sleep and illness. Matt was nine weeks premature, but relatively healthy. He was diagnosed promptly, receiving a tracheostomy at age 6 weeks. Thanks to the home ventilator program at Riley Hospital for Children in Indianapolis, we brought Matt home, just shy of 6 months of age, with a Sechrist infant ventilator, 24-hour nursing care, and apnea and CO₂ monitors. When he was 1 year, Matt switched to an LP6 ventilator, using it only during sleep or illness. With no other major accompanying conditions, such as Hirschsprung's disease, Matt has been very stable medically and has never been hospitalized for illness.

When Matt was almost 7 years, we began discussing the idea of noninvasive ventilation with Drs. David Westenkirchner and Deborah Givan at Riley Hospital. We had heard, through the CCHS Family Network, that some families had successfully made the switch. Matt was very motivated to get rid of his trach, socially feeling his physical

difference due to the trach. He was also beginning to experience more upper respiratory infections. We felt the time was right.

The plan, after a baseline sleep study on the LP6 in April 1993, was to try the BiPAP® system, adjust the settings, conduct another sleep study after six weeks, then decannulate after six months. Matt adjusted very well to the small Respironics mask with a comfort flap and did not try to take it off. Before the followup sleep study, we all attended the CCHS family conference in Michigan, with Matt using the mask. We met two other families also using the BiPAP® system, and it was reassuring to see other families who had or were in the process of making the switch. One child was a veteran of nasal ventilation; his trach was closed and he was doing very well. The other child kept taking the mask off during the night (although she eventually changed masks and is now doing fine). We fell somewhere in between. Matt was accepting the mask, but was having intermittent low oxygen saturation alarms during upper respiratory infections.



The followup sleep study in October 1993 showed that Matt was still desaturating, and the doctors were perplexed. A simple X-ray determined that Matt's adenoids were enlarged; he needed a tonsillectomy and adenoidectomy, and they were performed in January 1994. By this time, we were weary, but still determined to make it work, and luckily Matt's physician, Dr. Givan, was too. Dr. Givan wanted to wait until spring to give Matt's airway a chance to heal before trying again. Finally, Matt was decannulated in July 1994. His stoma never closed and he had tracheal cutaneous fistula surgery in November 1994. The stoma site healed within two weeks. It was a long, hard, stressful road, but well worth it.

We have found (from a tip by a CCHS family in Utah) that a soft cervical collar helps maintain neck extension and keep the mouth closed, thus eliminating low O₂ saturations. Matt has had only minor facial breakdowns from the mask, which is remedied by 3M micropore tape placed directly on his skin. The comfort flap on the Respironics mask has made a big difference in alleviating skin breakdown.

Matt is more alert, has gained weight, and his speech and articulation have improved. He missed

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COMPARISON OF COMMERCIAL & CUSTOM NASAL/FACE MASKS

*prepared by Susan Sortor Leger, RRT, for the
Fifth International Conference on
Pulmonary Rehabilitation and Home Ventilation,
March 12-15, 1995, Denver, Colorado*

COMMERCIAL NASAL MASKS

Manufacturer	DeVilbiss	Healthdyne	LIFECARE	Vacumed	Puritan-Bennett	ResCare	Respironics
Name	DeVilbiss Mask & Seal-Ring Kit	Healthdyne Technologies Soft Series™ mask	LIFECARE Software® nasal mask	Comfo-Seal & SI style masks	Companion nasal CPAP mask	Sullivan Bubble Mask System Series I, II, III	Silicone contour masks & comfort flap
Material	Non-latex, hypoallergenic Tactylon	Silicone	Isoloss CF molded urethane foam	Urethane foam; vinyl	Spun lycra	Medical grade silicone	Disposable: vinyl Nondisp: silicone Flap: polyurethane
Description/Features	C-flex material for greater comfort & patient compliance. Adapts to all 22mm tubing.	Adjustable position of lower head-gear straps.	Seal made of contoured "memory foam;" conforms to variety of facial configurations.	For people w/ sensitite skin & allergic reactions to silicone.	Soft vinyl cushion minimizes leaks & patient discomfort.	Ultra thin silicone membrane for skin comfort. Pliable, conforms to facial features.	Designed to fit facial contours to create better seal.
Swivel	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Sizes	3	7	6	5	3	5 in each series	7
Air Inlet Location	Center front	Top	Center front	Comfo-Seal: top SI: center front	Base	Center front	Center front
Headgear	4-point soft cap; open 4-point crown strap.	4-point soft cap; open 4-point crown strap.	Single strap; 3-point; and 3-pt. conversion strap.	4-point and 4-point w/ chin strap.	4-point snugfit	Breatheable; 5 sizes: 3-pt. 4 sizes: 5-pt.	4-point soft cap; open crown strap.
Replacement Frequency	Mask nondisposable; Seal ring cushion 1/mo	6 mos-1 yr	Mask nondisposable seal: 3-6 mos	Mask: 6 mos-1 yr Cushion: 6 mos	6 mos-1 yr	6 mos-1 yr	Mask (nondisp): 1 yr Flap: 4-6 mos
Weight (gr)	56	39.2	35	Comfo-Seal: 70 SI: 56		33	51.1 w/flap
Suggested (\$) Retail Price	Mask/2 seal rings: \$66.50 4 rings: \$27	Mask: \$41	Mask/seal: \$66 Seal: \$26	Comfo-Seal: \$49 Seal: \$12 SI: \$34.95	Mask: \$41.65	Mask kit: \$140 Mask frame: \$45 Ser. I cush: \$45 Ser II cush: \$65 Ser III cush: \$70	Disposable: \$70/5 Nondisposable: \$51 Flap: \$55/5

CUSTOM NASAL MASKS

Manufacturer	LIFECARE	LIFECARE	LIFECARE	SEFAM	Remmer	Bach
Name	Thermoformable	Standard	Integral	Anatomic	Remmer mask	Bach
Material	Silicone base paste	Silicone base paste	Silicone base paste	Silicone base paste	Acrylic, light, cured	Acrylic
Description/Features	Made directly on patient's face; reinforced tubes direct air to nares w/in low-profile custom-made shell.	Made directly on patient's face; standard shell w/ 2-point fastening system. Adult or pediatric kits. Easy to make w/ low profile.	Made directly on patient's face; different style standard shell w/3-point fastening system - stable.	Made on plaster mold with anatomically-shaped profile, custom-made shell.	Made on plaster model of patient's nose.	Made on plaster model of patient's nose.
Swivel	Not necessary	Can be added	Can be added	Not necessary	Not necessary	Can be added
Headgear Style	2 or 4-point	2-point	3-point	2 or 4-point	Headband	Any variety
Replacement Frequency	Every 6 mos-1 yr	Every 6 mos-1 yr	Every 6 mos-1 yr	Every 6 mos-1 yr	Every 8-10 mos for headgear & tubing. Over 3 yr for mask.	Every 8-10 mos for headgear & tubing. Over 3 yr for mask.
Weight (gr)	70-128	60-98	50-95	30-50	25	50

COMMERCIAL FULL FACE MASKS

Manufacturer	Med Systems	Puritan-Bennett	Respironics	Vacumed	Taema	Bird
Name	Meds Ser. 2000	Benefit	Disposable full face mask	Full face mask	Foam face mask	Face mask
Material	Polyurethane	Silicone		Silicone	Latex	Latex
Swivel	No	Yes		Yes	Can be added	Can be added
Sizes	3	3 adult 4 child/infant	4	3 adult 2 child/infant	2 adult 1 child/infant	3 adult 4 child/infant
Air Inlet Location	Front center	Front center	Front center	Front center	Front center	Front center
Headgear Style	4-point	4-point		4-point	4-point	4-point
Replacement Frequency	Disposable; every few days	1/yr		1/yr	Foam every 3 weeks	1/yr
Weight (gr)	49	Adult: 45		182	54	
Suggested (\$) Retail Price	\$2.50			\$139		

COMMERCIAL NASAL SEALS

Manufacturer	Healthdyne	Puritan-Bennett	La Diffusion Technique
Name	Nasal seal	ADAM circuit	MIN
Material	Silicone	Silicone	PVC
Swivel	Yes	Yes	No
Sizes available	1	3	1
Sizes/Types of Seals	Flat, Mushroom	Standard, Dilator	Small, large
Replacement Frequency	Every 2-3 mos	Every 2-3 mos	Every month
Weight (gr)	36.4	60	64
Suggested (\$) Retail Price	Mask: \$68.95 Seals: \$15.95	Mask: \$44 Seals: \$22.15	NA

ADDRESSES

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B-239, 150 Bergen St.
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Bird Products

1100 Bird Center Dr.
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619/778-7200

DeVilbiss Health Care, Inc.

P.O. Box 635
Somerset PA 15501-0635
814/443-4881

Healthdyne, Inc.

1850 Parkway Pl.
Marietta GA 30067
404/423-4500

La Diffusion Technique

114 a 120 Rue Bergson
B.B. 132
F-42003 Saint/Etienne
Cedex
France

LIFECARE International, Inc.

Park Centre
1401 W. 122nd Ave.
Westminster CO
80234-3421
800/669-9234

Med Systems

2210 Wilshire Blvd.,
Suite 376
Santa Monica, CA 90403
800/345-9061

Puritan-Bennett Corp.

4865 Sterling Dr.
Boulder CO 80301
800/248-0890

Remmer Mask

Remafa Tech.
Pliggvagen 34
S-126 39 Hagersten
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ResCare

5744 Pacific Center Blvd.,
Suite 311
San Diego CA 92121
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Respironics Inc.

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A WELL-TRAVELED VENTILATOR USER

by Anne Isberg

During the past 20 years, I have been commuting between Europe and the United States. My respiratory insufficiency, due to poliomyelitis contracted during an epidemic in Denmark in 1952, was and is rather severe. In 1981, my breathing deteriorated, and a tracheotomy (performed in Copenhagen) became necessary. Although I use a ventilator (PULSULA III) all the time, I can breathe on my own for short periods. The tracheotomy changed many things in my life. It removed my fear of being together with people and contracting cold viruses from them. My energy level rose. My feeling well increased. My voice level rose and suddenly even I could be heard in a crowd.

I have crossed the Atlantic 82 times, and more than 37 since the tracheotomy. I attended the post-polio conferences in St. Louis (organized by G.I.N.I.). Certain airlines, such as KLM and SAS, provide an electrical outlet at my seat for the ventilator. They provide assistance in boarding, and they transport my electric wheelchair in the baggage compartment free of extra charge. I sit in an aisle seat, usually near the cabin crew's area. On the newer planes, the armrest of the aisle seat lifts up to make transferring much easier.

On long flights, it is essential that the airlines provide one with whatever electricity is needed from the aircraft, because it would be very difficult to carry enough batteries to power the ventilator. On short flights I do carry a battery for the ventilator. Even with everything planned as best as possible, things can go wrong, and I carry a few tools and a resuscitation pump. My pump is a little different because it is an air mattress pump equipped with all the appropriate connectors and fittings so that the person traveling with me can have his hands free to help me in other ways during an emergency situation. In my baggage, I also carry a small unit for suctioning.

As Hans Christian Andersen said, "To travel is to live," and I agree. One expands one's knowledge learning foreign cultures, other ways of thinking and doing things. For instance, it has been interesting to see how differently respiratory insufficiency has been treated in the U.S. and Denmark, especially the reluctance in the U.S. against tracheotomies. I have met several Americans using a variety of mouthpieces with positive pressure ventilators, many of whom I could barely hear and whose means of expressing themselves was so inferior that communication was difficult. It made me feel guilty that I was able

to speak so much better than they and that I knew they could be doing so much better.

However, American attitudes towards people with disabilities seem so much more natural and have been very nice to experience. Disabled people seem to be treated as equals. President Roosevelt and Senator Dole have been able to serve their country in spite of their various physical disabilities. This is unique for the United States of America! This is why America is so nice to visit. One is being regarded as a human being, not just some wreck.

In the little suburb of Houston where I stay most of the time when in the U.S., I am a familiar sight on the streets. Little children have stopped at the house asking for "the lady with the broken legs and the hole in the throat." Everybody knows me and seems to be looking out for me.

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

Personal Perspective

by Ritva Laine-Mammi

When I began using a ventilator 13 years ago, I was almost the only person in Finland who had a neuromuscular disease who used a ventilator, perhaps excluding Kalle Konkkola, chairman of Disabled People's International. In my experience, I tried to find out about my condition and my future, but nobody would tell us anything. Anxiety was great. I felt frightened and embarrassed about many things. Simply the fact that the disease has suddenly gone worse is enough to make you depressed. This feeling is all the greater because you are now much less free and much more dependent on other people.

I have had to adopt a new attitude time and again over the many phases of my disease. Nevertheless, the ventilator was something totally different and meant a huge change in my life. Physically, the adaptation took four months, but mentally the process took two years.

Before the ventilator, a few young girls used to take care of me for eight hours per day (paid by the State) while my husband went to school. After the ventilator, the system changed, and the girls worked in two shifts from morning to evening. We had to find a larger apartment to accommodate the ventilator and related equipment.

The present situation of respiratory paralysis patients almost horrifies me. In the hospital, people are attached to the machines, but everything else remains unclear to them. I thought I was strong and a survivor, but in the end, I was almost crushed by red tape. If my husband had not supported me then and now, I do not know what would have happened. It is necessary to have a family around to support you. What life is like depends a lot on the practical arrangements and circumstances.

Legal Perspective

by Jari Korpi, LL.M.

In Finland, there used to be a special law about respiratory paralysis patients (RPPs) and their treatment at home. The law was abolished in 1993, and now the treatment of such patients is part of the normal activities of a hospital. For financial reasons, there is a danger that the ventilator users would no longer be able to live at home, because it is said that their treatment is less costly in the hospital itself.

The act relating to RPPs was issued in the 1950s during a poliomyelitis epidemic in Finland. The purpose of these laws was to guarantee free medical treatment and board and lodging to these patients. The state also paid the costs of the treatment to the hospital.

The definition of RPPs in the legislation was a rather general one to start with: someone who needed treatment with a ventilator or similar machine due to a respiratory paralysis. The term respiratory paralysis as such was not defined in any way, although it was mentioned in the documentation that most, but not all, of these patients had poliomyelitis. On medical grounds, respiratory paralysees can be classified in three groups based on the cause of the paralysis: neurogenic, such as poliomyelitis, ALS, etc.; myogenic, such as muscular dystrophy; or injuries to the chest, lungs, or diaphragm.

When the Act relating to RPPs was reviewed in 1964, the Act was amended to cover only those RPPs who needed a ventilator for a longer period, later defined as more than 21 days. The need for a ventilator does not have to be continuous; it can be sporadic, if it is regular. Provisions on nursing at home and transportation for treatment were added.

A general reform in 1993 on payments by the State to municipalities and their hospitals based the payments on population, no longer aimed at a particular purpose. Before 1993, the municipality received payments on the basis of money spent on different purposes. In the new system, if certain costs rise, payments no longer rise with them. However, the municipalities and their hospitals are still obliged to perform the tasks assigned to them. There is a real danger that the financial situation of the municipality in which the patient lives becomes a determining factor in his or her treatment. It is clear that the hospitals are less willing to treat RPPs at home and to make proper arrangements for this nursing, due to economic reasons.

Despite the attempts of the hospitals to the contrary, if RPPs can be treated effectively at home, the hospital cannot deny them the right to live at home only on the basis of lack of funds. In 1988, the Supreme Court of Finland judged that such a patient had to be treated at home for free. The hospital had refused to provide funds for this purpose, but their decision was overruled.

In general, most people with disabilities are entitled to pensions in Finland provided that they are not in hospital treatment. When a RPP is treated at home at a hospital's expense, his or her

FINLAND: VENTILATOR USE

treatment is considered comparable to treatment within the walls of the hospital when considering the right to a pension, and therefore these patients are not entitled to pensions. This also means that it is virtually impossible to get rehabilitation, because it is generally given to persons who receive a pension.

Due to the current economic situation, it will become more and more difficult to organize proper home treatment of RPPs. Therefore, it should be specified in legislation that these individuals do not have to stay within the walls of a hospital as long as their condition allows them to live at home. Their status should also be made clearer as regards to other legislation, so that they would have equal rights to various services, rehabilitation, and pensions as do other people with disabilities.

ADDRESS: Lihastautiliitto R.Y., Muskelhandikappförbundet r.f., Lantinen Pitkakatu 35, 20100 Turku, Finland.

I.V.U.N. DIRECTORY UPDATE

This update is a companion to the Directory published in *I.V.U.N. News*, Fall 1994, Vol., 8, No. 2. Corrections and changes are underlined.

AUSTRALIA

Australian Ventilator Users Network
P.O. Box 211
Fairfield Victoria 3078

DENMARK

Dr. Henning Sund Kristensen
Maglebjergvej 6
DK-4295 Stenlille

FINLAND

Lihastautiliitto
Lantinen Pitkakatu 35
FIN-20100 Turku

GERMANY

Dr. Matthias Wiebel
Thoraxklinik
Amalienstr. 5
D-6900 Heidelberg

USA

California

Tony Hilton, RN, MPH, CRRN, CCM
Loma Linda Univ. Med. Ctr.
909/824-4495, pager 8304

Deceased:

Ed Roberts*

Colorado

National Center for Home Mechanical Ventilation
Karen Glenn, RRT
1400 Jackson St.,
Room J105a
Denver CO 80206
303/398-1949

Ohio

Teri Nikolai Wilson, RRT, CPFT**
The Children's Medical Center
One Children's Plaza
Dayton OH 45404
513/226-8300, pager 380

Texas

Deceased:

Susan Ray*

*ventilator user

**pediatric interest

MATT

 Continued from page 5

only two days of school this year, compared with 10 days last year, and has discontinued his antibiotics. He will be able to participate in swimming and other sports. The psychosocial benefits are obvious. Only after his switch to the BiPAP® system did Matt tell us that the other children picked on him. Now Matt is treated just like one of the gang. He's in Cub Scouts, takes classes at the zoo and children's museum, loves video games, riding his bike and all the other things a 9-year-old boy does. Matt wants to be either a paleontologist or an ice cream vendor when he grows up.

ADDRESS: The Stone Family, 4616 Melbourne Rd., Indianapolis IN 46208.

KATHRYN

by Jo Moore

Born with muscular dystrophy, Kathryn is almost 9 years old. She had pneumonia at 5 years, which led to a tracheostomy and LP6 ventilator, and a G-tube for supplemental nutrition. Severe scoliosis required back surgery for spinal fusion and placement of rods.

Kathryn lives on a mountain with her parents, friend Susan, and dogs, cats, guppies, and pet rat. She is in third grade and involved with the local Brownie troop. When feeling well, Kathryn is up in the morning, off the vent, and running the house from her power wheelchair. Her favorite pastime is making up stories and playing make-believe. Frequent visitors are the highlight of her life.

ADDRESS: The Moores, P.O. Box 1096, Cobb Mountain CA 95426.

Deadline ...

for submission of articles, stories, information, etc., for the Fall 1995 issue of *I.V.U.N. News* is August 31, 1995.

Please mail or fax to:

I.V.U.N. News
5100 Oakland Ave., #206
St. Louis, MO 63110-1406 USA
314/534-5070 FAX

❑ **NETLEY WATERSIDE HOUSE**, in Southampton, England, southwest of London on Southampton Water, is a unique vacation facility for people with disabilities and their families. Started in 1977, largely by Dr. Geoffrey Spencer of St. Thomas' Hospital, Netley has a special wing, the Kevin Black Centre, especially for ventilator users. Refresh (Resort For Responaut's Seaside Holiday) is the registered charity which subsidizes the cost and plans activities. Provided are accommodations with private bath, complete ventilator equipment support, meals, transportation, etc. Cost per week during peak summer holidays is £560, with some extra charged for family. For more information contact Refresh, Room 6, Lane-Fox Unit, St. Thomas' Hospital, London SE1 7EH England.

❑ **HOME MECHANICAL VENTILATION**, the proceedings from the Lyon meeting in March 1993, are now available for \$65 (USD). Contents of the 384-page book include organization and ethics of home ventilation; methods and techniques of longterm home ventilation; pathophysiology, longterm home ventilation and chronic respiratory insufficiency; use of continuous positive pressure in sleep apnea syndrome; and outcomes and indications for longterm home ventilation. Order from Arnette Blackwell, Departement Librairie, 2 rue Casimir Delavigne, 75006 Paris, France. Fax int. +33.1.46.33.67.97.

❑ **STANDARDS OF CARE FOR THE ASSISTED INDIVIDUAL: A COMPREHENSIVE MANAGEMENT PLAN FROM HOSPITAL TO HOME** by Adrienne Baldwin-Myers, MS RN; Michele Geiger-Bronsky MSN RN; Alison Chacona RRT; Bonnie Huiskes MSN RN; Lynn Ewing RN & Jane Shiroma RN. Available for \$10 postpaid from Loma Linda University Medical Center, Nursing Staff Development, P.O. Box 2000, Loma Linda CA 92354.

❑ **NEW ADDRESS** for LIFECARE International, Inc.: Park Centre, 1401 W. 122nd Ave., Westminster CO 80234-3421. 800/669-9234.

❑ **AVAILABLE:** Ventilators, accessory equipment, travel trailer, and more. Some items free. For specifications, write or call the I.V.U.N. office, 5100 Oakland Ave., #206, St. Louis MO 63110-1406. 314/534-0475 or FAX 314/534-5070.

Calendar

CCHS FAMILY CONFERENCE: VENTILATOR OPTIONS & RESEARCH DIRECTIONS IN CCHS, June 22-25, South Seas Plantation Resort, Captiva, Florida. Contact Nancy Stone, 4616 Melbourne, Indianapolis IN 46208. 317/299-0801.



EUROPEAN RESPIRATORY SOCIETY ANNUAL MEETING, September 16-20. Barcelona, Spain. Contact ERS office, 60, rue de Vaugirard, F-75006 Paris, France.

BACK ISSUES

Back issues of *I.V.U.N. News* from 1987-1994 are still available. Individual issues are \$3 each and a complete set of 16 can be had for only \$20 postpaid from I.V.U.N., 5100 Oakland Ave., #206, St. Louis MO 63110-1406 USA. Issues are broadly indexed below:

Advice for new ventilator users - Fall 1993
Air scuba - Fall 1993
Anesthesia in severe disability - Fall 1989
BPD - Spring 1994
Batteries - Spring 1990
Breathing failure in ALS - Fall 1990
CCHS - Fall 1992, Fall 1993, Fall 1994
Caregivers of ventilator users: survey - Fall 1994
Children as ventilator users: feature - Fall 1993
Cofflator revisited - Spring 1993
Communication for ventilator users with trachs - Spring 1993
Cough - Fall 1994
Denmark: ventilator use - Fall 1992
Diaphragm pacing - Fall 1994
France: ventilator use - Fall 1994
Home care - Spring 1990, Fall 1994
Iron lung users guide - Spring 1988
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Muscular dystrophy - Fall 1989, Fall 1994
Nasal masks - July 1987, Spring 1994
Noninvasive ventilation - Spring 1989, Fall 1989, Spring 1994, Fall 1994
Quality of life - Spring 1990, Fall 1994
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Sailing - January 1987, Spring 1993
Spinal cord injury - Fall 1990, Fall 1992, Fall 1994
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Travel - Spring 1992, Fall 1992
Underventilation - Fall 1988
Ventilator history - Fall 1989, Spring 1993
Ventilators: lease vs. purchase - Fall 1991

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1995 CAMPS FOR VENTILATOR-ASSISTED CHILDREN

April 1-7. Ventilator-Assisted Children's Center (VACC) Camp,
Miami, FL. Contact Cathy Klein, VACC, 3200 S.W. 60th Ct., Suite 203, Miami FL
33155-4076. 305/662-VACC.

June 3-9. 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 25-30. Camp Harmony Hall, Middletown PA. Contact Pam Smith,
CRTT, Pennsylvania Vent Camp, P.O. Box 60443, Harrisburg PA 17106-0443.
717/671-0226.

July 9-13. 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.

July 30 — August 5. CHAMP Camp, Recreation Unlimited, Ashley, OH.
Contact David Carter, RRT, CHAMP Camp, P.O. Box 40404, Indianapolis IN
46246. 317/872-0555.

August 31 — September 3. SKIP Camp, Seashore United Methodist
Assembly, Biloxi, MS. Contact Judy Abney, SKIP of Louisiana, 118 Ned Ave.,
Slidell LA 70460. 504/649-0882.

