

Longterm Ventilation for Children in the United Kingdom

Dr. Robert Yates, MBBS, MSc, MRCP, FRCPC, DA

In the United Kingdom, there are approximately 150 children who are ventilator-dependent. They have a variety of underlying diagnoses and ventilation needs but are medically stable and suitable to be supported in the community. Until recently many of these children had to spend long years in District General Hospitals or even in ICUs. This was because of the difficulties in arranging home care programs. Funding for such projects is costly, and there has been no provision for it within the complex contracts that exist between purchasers and providers of health care in the National Health Service.

The purchasers are the Health Authorities (HAs), responsible for providing health care to regional populations of up to 500,000 people. The providers are tiered as primary, secondary, and tertiary. Primary care providers are the family doctors or GPs. Secondary care providers are the District General Hospitals – usually one within each HA – providing most inpatient services, and the Community Trusts which control all aspects of community medicine, such as geriatrics, mental health, paediatrics, and also work closely with Public Health. The tertiary care providers are usually university hospitals with specialist departments serving an entire region which can also provide secondary care for their local population. Specialist paediatric services, e.g., neurosurgery, endocrinology, cardiology, and intensive care, are based in these centres.

Each HA must arrange contracts with the secondary and tertiary care providers to ensure the health needs of its population are met in line with its policies. If these services are outside of the contracts, it is very difficult to get funding for anything else.

teenagers and their future needs have to be considered. This is a new drain of resources for both Social Services and the Community Trusts and is often fiercely contested. As each Community Trust may only have one such child, recruitment and training for the



(l to r) Macauley, Amanda, and Ian in Transitional Care Unit at the Royal Manchester Children's Hospital.

As a tertiary care provider, we at Royal Manchester Children's Hospital recommend a package for a particular child to the Community Trust. If the Trust agrees to accept responsibility for the child, they must receive special funding from the HA for that child – for equipment costs, caregivers, and nurses. Once funding for a particular child's health care at home has been agreed, we then face the task of securing funds from the Social Services budget for housing adaptations; remembering that small children grow to be larger

teams are the next hurdles. It is little wonder that these teams feel isolated and unsupported without the benefit of any respite facility and with a variable level of interest from the local District General Hospitals.

The package we usually suggest consists of 5.8-6.4 full-time equivalent staff for a 24-hour ventilator-dependent child, consisting of two Registered Sick Children's Nurses and "trained caregivers." There is currently provision for ongoing physiotherapy, or

occupational or speech therapy in the community. Respiratory therapists do not exist in the United Kingdom, and any ventilator changes are done by the physician. We try to provide guidelines for practically everything in order to support the Community Trust teams who are supposed to be self-perpetuating in terms of recruitment and training.

There is no budget for ongoing training although some of the teams are part of wider Community Trust paediatric home care teams, e.g., specialist feeding, IV teams, etc. The family doctor will be aware of the child under his/her care, but will generally have little to do with the ventilation aspects as there is often no out-of-hours medical support from the Community paediatricians. The District General Hospital where the child lives may actually refuse to manage a ventilated child on its wards, in which case the child may have to be admitted to the regional ICU.

This is the paradox: on one hand we say that children can be safely and effectively managed at home, but on the other hand centralization of intensive care services dictates that all children requiring ventilation should be managed in ICUs. Anyone who has to watch parents walking daily past the other desperately ill children in the ICU or who has to explain to a longterm ventilated child why the other children may have died cannot help but be moved.

The United Kingdom Paediatric Longterm Ventilation working group is a body of interested health care professionals who are developing guidelines to streamline the path home for these children. Following a study funded by the Department of Health in 1996 into the numbers of children in the United Kingdom

requiring longterm respiratory support, the group has been coordinated by Dr. Colin Wallis and Sister Elspeth Jardine at Great Ormond Street Children's Hospital in London. We hope to expand the work of the group to include support for children, parents, and caregivers with advice on equipment, strategies, and networking through our Web site: www.man.ac.uk/Med/tcu/index.html.

As Consultant in Paediatric Intensive Care at Royal Manchester Children's Hospital, I currently have contact with about 20 children around the region who are dependent on mechanical respiratory support. This ranges from overnight ventilation supervised by parents or caregivers to 24-hour ventilation with 24-hour nursing support in a variety of care facilities or at home.

In autumn 1997, our hospital opened a Transitional Care Unit, specifically for these children, away from the ICU. The emphasis is on high intensity therapy and preparing the children and their families and caregivers for life at home. We try to make the ventilation aspects of care as unobtrusive as possible with minimal monitoring and reliable but low-key portable equipment. The unit has four beds although we are trying to develop a flexible fifth bed. This would be used for respite, reviews, and assessment of ventilation needs of older children with myopathies and other conditions.

We accept all children post special-care baby units, although they can be any age from 3 months to 18 years. Intensive therapy includes postural drainage, clapping, cupping and percussion techniques, as well as stretching and other exercises, swimming, etc. Occupational therapy provides technology. There are daily programs of

therapy with play incorporating speech, language, and physiotherapy.

Three children are on the unit. Ian, age 8, has a high spinal cord injury. Amanda, age 7, has nemaline myopathy. Both she and Ian attend school across the city. Macauley, age 3, has CCHS and enjoys a local playgroup. All have tracheostomies. (I favour Bivona cuffed tubes with cuffs partially inflated and the Breas 401. I also use bi-level pressure support, such as Respironics BiPAP® systems and Friday Medical's Nippaed, Nippy, and Nippy 2.)

Our nurses try to make the 'ward' as much like home as possible with an informal approach and defined teams for each child. The children have the opportunity to do so much more on and off the unit than when on the ICU. They regularly undertake trips to the supermarket, cinema, or picnics in the park – sometimes they seem to disappear for days at a time. The unit is friendly and alive with the buzz of activity and the noise of children playing, but very flexible nursing and staffing levels are required.

Unfortunately, the demand for the unit far exceeds its capacity and some children remain in ICUs whilst we try and arrange for their discharge either back to their local hospitals or sometimes straight back to the community – a process which can take years. Despite all these problems the future is brighter now for these children than ever and we have a wonderful opportunity to build a new service to help them achieve their maximum potential. ■

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Speak to Me

Jeannette D. Hoit, PhD

As a speech scientist and speech-language pathologist, I have a keen interest in the communication challenges of people with tracheostomies who use ventilators. My interest was sparked several years ago during a conversation with Robert B. Banzett, PhD, a respiratory physiologist at the Harvard School of Public Health, about issues related to breathing for speaking. Bob commented that people who use tracheostomy positive pressure ventilation speak during inspiration. I didn't believe him. It seemed to me that speech should be produced during expiration, not inspiration.

I had not yet met anyone who used a ventilator, so Bob took me to meet Sue, who had used positive pressure ventilation for over 20 years. I quickly saw that Sue was indeed speaking during the inspiratory phase of the ventilator cycle. Although our discussion might have ended there, Bob and I, along with Steven A. Shea, PhD, decided to conduct a formal research study designed to elucidate how speech is produced by people with tracheostomies who use positive pressure ventilators (Hoit, Shea, & Banzett, 1994).

Our research showed that people using positive pressure ventilators (at least the people we studied, under the conditions studied) spoke during both inspiration and expiration. We learned a great deal more about the details of how ventilator-supported speech is produced and began to formulate ideas about how such speech might be improved. With Bob and Steve's expertise in respiratory physiology, mine in speech production, and support from our collaborative relationships with

top-notch pulmonologists such as Robert Brown, M.D., Brocton/West Roxbury Veterans Administration Medical Center, we realized we could make contributions toward improving spoken communication in ventilator users.

The people who participated in our research have neuromuscular disorders, such as spinal cord injury, muscular dystrophy, and amyotrophic lateral sclerosis. They have tracheostomies and are longterm ventilator users. They can tolerate having the cuff deflated on the tracheostomy tube. Speaking requires that the cuff be deflated or that the tracheostomy tube be fenestrated in order for some air to flow through the larynx. This air flow enables the vocal folds to vibrate to create the sound source for the voice. Some people are unable to tolerate having air leak around or through the tracheostomy tube, but many people can tolerate it (Bach & Alba, 1990). If an air leak can be tolerated, it can mean the difference between being able to speak and being sentenced to silence. (There are other ways to produce voice, such as artificial voice, but a discussion of these is beyond the scope of this article.)

Allowing some air to flow through the larynx is a critical step toward having effective speech, but even then problems can exist that cause the speech to be less than optimal. The problem that is usually most noticeable to the listener and most disturbing to the speaker is that the timing of speech can be off. Spoken phrases are often much too short, and the pauses between them much too long. Short phrases and long pauses make it difficult to carry on a conversation because speech is often cut off in mid-sentence, it takes many more breaths and much more time to express an idea, and because even the most well-mean-

ing conversational partners tend to interrupt during the pauses.

Perhaps the most difficult situation is a telephone conversation. If the ventilator breath is not perfectly timed, the operator's hello may be greeted with silence; if the silence lasts too long, the operator may hang up. According to many ventilator users, it is this speech timing problem that creates the most frustration.

Another problem often experienced is that the voice may be uneven in loudness and quality. Over the course of a breath cycle, the voice may start out adequately loud and then gradually become too soft to be heard. Or the voice may start out sounding a little strained, become a little breathy, and then become clearer later in

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Conversion: Iron Lung to Porta-Lung?

Carol Purington

After 42 years, Carol is trying to switch from night-time use of an iron lung to a Porta-Lung powered by the NEV-100. Carol contracted polio in 1955 at the age of 6. Since early May 1998, she has been experimenting with pressure settings and gradually increasing time in the Porta-Lung.

In April 1998, I had a momentous visit from the Boston district manager for Respirationics, Michelle Schweiger, who told me that it is becoming increasingly difficult and expensive to keep parts and trained mechanics available for the iron lung. (See box.)

We discussed the advantages of switching from the iron lung to the Porta-Lung, a smaller, lighter, fiberglass version of the iron lung that provides equally effective ventilation. Its power source, the NEV-100, would also run my chestpiece.

I decided to undergo a trial period (free) with the Porta-Lung in May. If I was going to attempt such a change, I definitely wanted to do it when healthy and rested, when convenient for my family, and when decisions could be made slowly. Obviously, there would be both physical and psychological adjustments.

One of my brothers made a stand for the Porta-Lung, which comes on very short legs, rather like a dachshund. The stand, made of plywood and two-by-fours, is on casters so it rolls easily. It brings the large model (140 lb.) Porta-Lung up to hospital bed height and takes up about as much floor space as the iron lung.

The mattress is comfortable, the headrest stable and level with the mattress, and the pillow a good firmness. The collar is identical to that of the iron lung, as is the mirror. The appearance of the front of the Porta-Lung is also familiar, except for the blue color, but the mirror view of its see-through door is startling. I felt like Sleeping Beauty in her glass case.

With the door closed, there is very little space between it and my left elbow. The Porta-Lung is several inches narrower than the iron lung (large size is 84" long and mattress width is 23"), and I was conscious of a confined sensation. Different positioning corrected that.

The NEV-100 is computerized, with menu-driven settings. The whoosh-whoosh rhythm of the inspiration/expiration cycle is punctuated by a noise rather like the chirp of an electronic bird. It comes well-equipped with alarms, adjustable in pitch and volume.

The first session to work out approximate pressure settings was very fatiguing. I had to rely on the Porta-Lung to breathe for me, of course, because otherwise how could I tell if the settings were right? There is no other way, but it certainly was an exhausting process. There is psychological stress, as well, trying to ignore the lack of sufficient air while concentrating on what is wrong with the settings. By the end of the session, I was being fairly well ventilated by the Porta-Lung.

Becoming accustomed to the new rhythm went more slowly than I expected. The feeling of how it breathes for me was very different, somehow jerky – not uncomfortable and not exactly unpleas-

ant, just different. I still felt tired after each practice. After I managed six hours at a stretch, I tried sleeping in the Porta-Lung.

The experience of the first night in the Porta-Lung was somewhere between great and dreadful. I woke up much too often to say I slept well, but I was never in enough distress to be counting the hours until morning.

My first double-header in the Porta-Lung went fairly well, the second night better than the first. But going back into the iron lung on the third night felt wonderfully familiar and refreshing. I started a chart on which I record various aspects of my nights – breathing comfort, restedness, quality and quantity of sleep, etc. The scores for the times in the Porta-Lung were 54% and 60%; the iron lung's score was 88%.

I decided to talk with Sunny Weingarten, fellow polio survivor

Ventilator Obsolescence

Many polio survivors are experiencing difficulty in getting their older Bantams, blowers, 170-C equipment, and iron lungs repaired. For Respirationics, which maintains this equipment, it is becoming increasingly harder to find a reliable supplier of the parts with the same quality at a reasonable price. As long as parts are available, Respirationics will continue to service the equipment. However, the company strongly urges that people using the older machines think about making a conversion to the newer NEV-100 or the PLV-100.

Many iron lung users are interested in obtaining spare parts for their iron lungs. Anyone with iron lungs no longer in use or in need of parts should contact IVUN (314/534-0475; 314/534-5070 fax; gini_intl@msn.com).

and inventor and manufacturer of the Porta-Lung. He is friendly, sympathetic, and informative. I would have had an easier time with the pressure settings if I had called him sooner.

Several problems still need solving. One is how to position myself for postural drainage so that my left side is higher than my right. The iron lung has a good mechanism for tilting the bed-frame, and I have tried tipping the Porta-Lung mattress, which has a rounded bottom making it easy to tip. The angle seems to provide sufficient left-side elevation, but it places unacceptable pressure on the right side of my neck. That is another problem: how to avoid

neck chafing. Also, my mother or other caregiver always works on my right side with the iron lung. My scoliosis means that caring for me from the left side is not the same as working from the right. The large Porta-Lung model I have only opens from the left. (The model with a right-side opening is only available custom-made, using the medium size as a base. It is almost as long as the large model, but the diameter is still the medium size – 20 inches – too small for my broad shoulders.)

By the end of July, I had used the Porta-Lung for 25 consecutive nights, and was sleeping and feeling well. One night I awarded the Porta-Lung a score of 94%. Soon

I will have to decide whether to make a permanent change from old to new – a major choice for me and my caregivers, especially my mother.

In addition to the central question of the adequacy of the Porta-Lung's ventilation, the attempted change has involved many subsidiary issues, which have all required thought and effort and research. I suspect each potential user will have different obstacles to overcome. ■

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Conversions: Pressure-Limited to Volume Ventilator

GARY PRESLEY

When Jeff Davis from LIFECARE (now Respironics) called about four years ago and suggested I change from the Bantam to the PLV-100, I was reluctant. Why leave behind the lively little machine that brought me back from respiratory collapse? I was addicted to the sound of the Bantam wheezing away into the night. I could not sleep without it.

I have always realized that technology means progress. The Bantam design dates back decades, and logic told me support for its maintenance and parts would dwindle. My Bantam had a single pressure gauge, a toggle switch or two, a fuse, and rotary dial – simple and effective. The PLV-100, on the other hand, sports four LCD readouts, seven rotary switches, and a pressure gauge. No denying this technological overkill caused me to catch my breath, if you will pardon the pun.

The PLV-100 is a volume ventilator, and that one factor – airflow being regulated by volume rather than by pressure – seems to be the fundamental difference for us, the person at the other end of the hose. If you think of it in that fashion, you will understand the complex assortment of gauges and dials only mask the simplicity of the changeover. Let the respiratory therapist balance the gauges and explain their functions. Your job is to learn how much volume will make you comfortable and the rate at which you want it.

The first thing I noticed was the quietness of the PLV-100. I also appreciated the decreased wear and tear on my nose from the nasal mask. I ran the Bantam at approximately 25 pounds of pressure to sleep comfortably. The PLV-100 delivers 1400cc of air at about 15 pounds of pressure. That missing 10 pounds of air pressure allows my nose to wake up nearly as refreshed as the rest of me.

My switchover went smoothly, although it would be deceitful to say someone changing from a Bantam to a PLV-100 will not need a period of adjustment. Mine was short, mainly requiring me to understand the lesser amount of pressure did not translate into a lesser amount of air. By the third night, the PLV-100 had become a member of the household. In fact, in the two instances when I have had trouble with the PLV-100 and been forced to rely on my spare Bantam, I found it much more difficult to reacclimatize myself to the Bantam.

Do I miss the Bantam? No. Would I encourage Bantam users to switch to the PLV-100? Yes. Will it be difficult for a longterm Bantam user to make the switch? I cannot answer for you. In my experience, I found the switch remarkably easy: a positive attitude about positive pressure.

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the breath cycle. Changes in the quality of the voice are influenced not only by the nature of the ventilator breath but also by the way in which the muscles of the larynx respond to the breath. The easiest way to hear fluctuations in loudness and voice quality is to say a vowel, such as *ah*, holding it out as long as possible.

Our research revealed a link between these problems of speech timing and loudness/quality fluctuation and an important physiological variable: tracheal pressure, the pressure within the tracheal tube. This pressure is instrumental in providing the drive that vibrates the vocal folds to create sound.

The threshold pressure is the minimum amount of pressure needed to vibrate the vocal folds. If the tracheal pressure drops below this level, the vocal folds will not vibrate, and the voice will fall silent. For speech sounds like *ah*, the threshold pressure usually is around 2-3cm H₂O. Normal tracheal pressure stays above this threshold almost continuously (except during inspirations), but the ventilator-delivered tracheal pressure stays above this threshold for only a short time. (See figure.)

In someone who breathes independently, tracheal pressure used for speaking is rather low (usually between 5-10cm H₂O), and the waveform is quite constant. Ventilator-delivered pressure has a rapidly rising, highly peaked, and rapidly falling waveform. The exact size and shape of the waveform differs from person to person and from ventilator to ventilator, and also can be modified by adjusting the ventilator.

The short phrases and long pauses characteristic of ventilator-supported speech are caused primarily by the tracheal pressure remaining below the threshold pressure throughout much of the breath cycle. There are long periods during which speaking is impossible because the vocal folds do not have enough pressure to vibrate.

The fluctuations in loudness and voice quality occur during the time that the tracheal pressure is above the threshold pressure. In general, loudness increases and decreases along with pressure, so it is easy to see why loudness would fluctuate given the nature of this pressure waveform. The quality of the voice also can be influenced by changes in pressure, because

these pressure changes can alter the vibration characteristics of the vocal folds, and because the muscles of the larynx often make adjustments in response to changes in pressure. With such large and fast changes in tracheal pressure, it is not surprising that the quality of the voice can range from strained to breathy to clear, all within a single breath cycle.

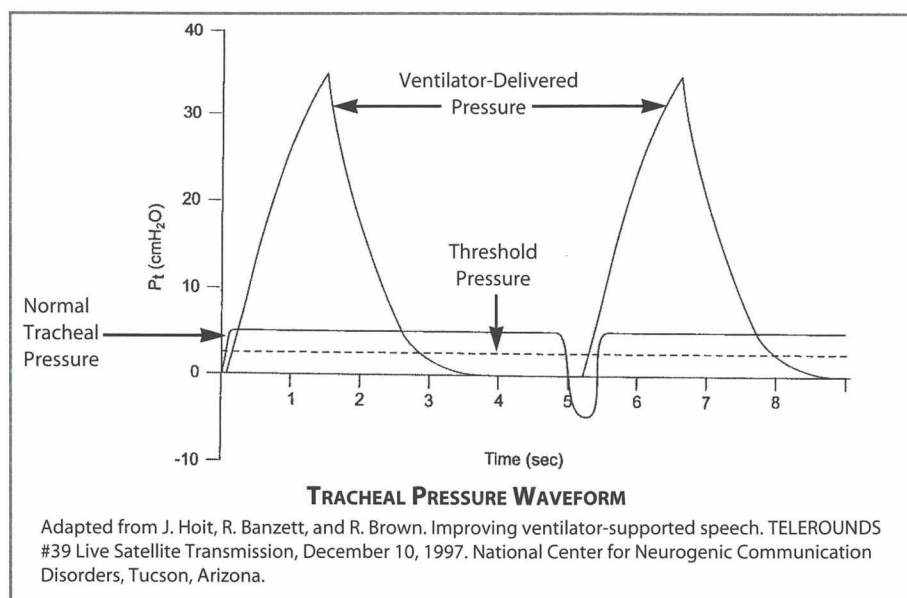
We have come to view the tracheal pressure waveform as a strong determinant of how speech will sound. In our quest to come up with ways to improve ventilator-supported speech, we have been exploring how to modify this waveform. Our goal is to find ways to create tracheal pressure waveforms that meet ventilation requirements, while at the same time maximize the potential for effective speech. In the next issue of *IVUN News*, I will update our current research on simple adjustments to the ventilator as a means to improve ventilator-supported speech. ■

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Research funded by James A. Shannon Director's Award (DC-02501), Research Grant (DC-03425), National Multipurpose Research and Training Center Grant (DC-01409) from the National Institute on Deafness and Other Communication Disorders, and Research Grant (HL-46690) from the National Heart, Lung, and Blood Institute.

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DICK WIELER

I left assisted breathing far behind after one year in a polio ward, graduating from the iron lung, the chest cuirass, and the rocking bed. However, after thirty years, the return to the use of respiratory equipment was troubling but necessary due to inadequate exchange of gases during the night and the need to rest a weak diaphragm. Sleep was very disturbed because of the buildup of carbon dioxide.

At my pulmonologist's suggestion, I tried nocturnal noninvasive positive pressure ventilation with a pressure-limited ventilator. Once I got used to the face mask, I was finally getting a good night's rest and feeling refreshed in the morning.

The switch from pressure-limited to volume ventilation occurred because my doctor was still not satisfied with my arterial blood gas (ABG) reading, which disclosed high carbon dioxide levels. Because a pressure ventilator only pushes air to a preset level, the actual amount getting into the lungs can be lessened by any obstruction, including the tightening of the chest cavity during long periods of being prone. In my case, allergies seemed to present a steady impediment, as did colds. A volume ventilator is set for a certain volume of air, regardless of the pressure. My doctor was able to set the adjustments adequately during an overnight hospital stay, using ABG to check the results.

I have been using the PLV-100 volume ventilator for several years now. It has the added feature of giving a larger breath upon demand, activated by consciously inhaling much like sighing. The unit is bigger and has more controls than my old pressure-limited ventilator, but it is easily mastered and very dependable. Breathing

during the night is much smoother, and I have less fear of colds. Of course, the hunt continues to find a mask that fits perfectly. However, the switch to the PLV-100 has been positive for me. ■

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Mechanical Ventilation Beyond the Intensive Care Unit: Report of a Consensus Conference of the American College of Chest Physicians, *Chest*, 113, May 1998 Supplement, 289S-344S
Chairman: Barry J. Make, MD, FCCP. Editor/Authors: Nicholas S. Hill, MD, FCCP, and Allen I. Goldberg, MD, FCCP.

An excellent, comprehensive review of home mechanical ventilation by a group of the most experienced health professionals in the field. Chapters cover management of both adult and pediatric ventilator users, noninvasive and invasive ventilation, discharge planning, ventilators and related equipment, and ethical issues. The report is available for \$14 (\$16 for other countries) from the American College of Chest Physicians, 3300 Dundee Road, Northbrook, IL (Illinois) 60062-2348 (800/343-2227 or accp@chestnet.org). ■

International Airline Carriers

(Follow-up to article in *IVUN News*, Summer 1998.)

KLM. 800/374-5774. Ventilator make, type, voltage and amperage requirements must be approved by technical department. KLM provides 12-V DC electrical outlet on most aircraft. Approval for dry batteries also required from technical department. No wet batteries allowed on board. ■

CALENDAR

1998

OCTOBER 16-17. Rehabilitation Approaches for the Tracheostomized and Ventilator-Dependent Populations. Minneapolis, Holiday Inn Select. Contact Professional Marketing Seminars, 949/597-0219 (pms@speechpaths.com).

1999

MARCH 3-5. Children Who Are Medically Complex or Technology Dependent: Safe at Home, Safe in the Community. Philadelphia, The DoubleTree Hotel. Contact Ken-Crest Services, 215/844-4620 (www.kencrest.org/medfrag/conf.html).

MARCH 14-17. 7th International Conference on Home Ventilation: Noninvasive Ventilation Across the Spectrum from Critical Care to Home Care. Orlando, Caribe Royale Resort Suites. Contact IVUN, 314/534-0475 (gini_intl@msn.com).

APRIL 5-11. Ventilator-Assisted Children's Center (VACC) Camp. Miami. Contact Bela Florentin, 305/662-8380, ext. 4610. Applications available through December 31, 1998.

Tracheostomy Support Group on the Web

Kelly Killough, mother of 3½-year-old Dakota, started a tracheostomy list on AOL for parents of infants and children with tracheostomies. Discussions have ranged from the quality of home nursing care to pulse oximetry and apnea monitors to cleaning of the trach to methods of communication to g-tubes to decannulation. Although the site is primarily for children, some adults have responded. It is an excellent source of hands-on experience and information. To become listed on TRACHTIES, e-mail: KEKILLOUGH@aol.com. ■

International Ventilator Users Network is supported by Mallinckrodt and Respironics.

IVUN Resource Directory 1998/1999, an excellent networking tool for health professionals and both longterm and new ventilator users, will be available in November. Sections are dedicated to health professionals, ventilator users, equipment and mask manufacturers, service and repair, organizations, etc. The cost is \$5 USA; \$6 Canada, Mexico, and overseas surface; \$7 overseas air (US funds only).

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**7th International Conference on Home Ventilation
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Topics include nutrition, secretion enhancement techniques, nocturnal hypoventilation, nasal masks, psychosocial aspects of longterm ventilation, quality of life, ALS, cystic fibrosis, swallowing disorders, transition from tracheostomy to noninvasive ventilation, and much more.

Hotel reservations: The Caribe Royale Resort Suites, 800/823-8300 or 407/238-8000. Ask for "ACCP/AARC Noninvasive Ventilation Meeting." The rate for a queen double room is \$159 per night (breakfast included), plus applicable taxes.

Airline reservations: For discounted travel, phone Ridgebrook Travel, 800/962-0560 or 847/374-0077. Delta Airlines contract #119851A; United Airlines contract #523XV. Ridgebrook Travel will also book rental cars through Avis, contract #J095524sa.

Registration: See enclosed registration form.