IVUN NEWS

International Ventilator Users Network (IVUN)
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Home Care and Mechanical Ventilation for Children in Thailand

Aroonwan Preutthipan, MD, FCCP

In Thailand, the respiratory home care program for mechanically ventilated children was formally established at Ramathibodi Hospital in Bangkok in 1995. Before then, almost all ventilator-dependent children had to remain in the hospital for months or even years. Only a few children who had strong family support could be discharged home.

Our program has been organized with cooperation between the pediatric pulmonology and pediatric nursing divisions. The multidisciplinary team involved in the case management and case monitoring includes pediatric pulmonologists, respiratory nurses, ambulatory (visiting) nurses, and a secretary to coordinate equipment.

There are four pediatric pulmonologists (including myself) and four fellows in the division. Our responsibilities are to select suitable patients for home ventilation, provide medical treatment, find and select appropriate equipment, and plan for discharge and follow-up care. The hardest work for us is when we have a child whose medical condition is suitable for home care, but whose family lacks financial resources. As the leaders of the team, we spend a lot of time seeking possible financial support for them.

Respiratory therapists do not exist in Thailand. On our team, respiratory nurses take on that role. Their main responsibility is training the caregivers, a very hard job because the caregivers are not health professionals and do not have any previous knowledge about respiratory care. In addition, our nurses have to prepare all necessary equipment, such as suction, resuscitation bag, oxygen device, etc. They also carry beepers 24 hours a day so that whenever any problem occurs the family can call for help.

The ambulatory nurses (similar to visiting nurses or home health care nurses in the USA) are also instrumental to the program. They regularly visit the patient at home. After the child is discharged home, the ambulatory nurses contact the family by phone and visit the patient at home once or twice a week. They assess the capabilities of the caregivers, give feedback, and notify the hospital team of problems.

Thai boy using BiPAP® via tracheostomy.

Since there is no medical equipment company that can provide a comprehensive set of respiratory home care equipment, our secretary is responsible for contacting sales representatives from different companies and asking for the necessary equipment. Her job is to collect all information on available equipment in the country and abroad, coordinate with equipment vendors, negotiate the price, and keep in touch with the families by phone, mail, or e-mail.

The organization of home care in Thailand differs from that in other countries in many ways. All expenses are directly borne by the family. Less expensive but safe mechanical ventilators are frequently used. Parents and relatives are the primary caregivers. The multidisciplinary team and the cooperation of the family are imperative for successful home care for mechanically ventilated children.

The major obstacle for home discharge is the lack of available funding. In Thailand, home care expenses are not covered by the government or insurance. The cost of equipment, supplies, and caregivers must be met by the family themselves. A number of patients whose conditions are suitable for home care still have to undergo long-term hospitalization unnecessarily because of the lack of family resources. The feasibility of home care depends very much on the family's resources and their ability to cope with ensuing problems.

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Because the cost of home care is directly charged to the family, the caregivers almost always are non-medical professionals. Home care nurses are not practical in Thailand since the cost is too expensive for ordinary families. Generally, parents, relatives, or nannies are trained as primary caregivers of the child.

One advantage is the extended family setting most common in Thai society. With two or three generations living together in the same house, one family member is selected as the caregiver. Experience has taught us that the level of the caregiver's education is not as important as dedication. Training these devoted caregivers is another key to the success of our program.

Conventional home mechanical ventilators in Western countries are not generally available in Thailand. Some are obtainable but too expensive. Some patients are lucky enough to receive home mechanical ventilators donated by charitable organizations and well-to-do people in society. Most ventilator manufacturers do not have sales representatives in Thailand so that obtaining service after the sale is difficult. The choice of ventilator is determined mostly by the price and safety. We are obligated to adapt and use ventilators manufactured for other purposes for home use.

Most of the mechanical ventilators we use in the home do not have internal batteries, and we have modified an automobile battery and connected it to an adapter changing DC electric current to AC current. This battery can be used in case the electricity is shut down while the patient is being ventilated.

The first case in our home care program was a 15-year-old girl with poliomyelitis. She was the first case we tried using BiPAP® invasively via tracheostomy. She had been using BiPAP® in the hospital comfortably for more than one year before the Rotary Club donated BiPAP® for her use at home. We selected BiPAP® because the patient was satisfied with this ventilator and because the price was only half of the other conventional home ventilators. The sales representative in Thailand was helpful, and we trusted that service after the sale would be provided.

After the first case, we then tried BiPAP® on a 3 1/2-year-old boy with CCHS. We did not try to use a nasal mask because the boy also has mental retardation and could not cooperate. The parents were trained to connect BiPAP® to the tracheostomy when the child fell asleep, but because BiPAP® does not have enough alarms, we recommended that the family use a pulse oximeter at night for monitoring instead. The father was the primary caregiver for this child; the mother worked for a telephone organization which covered parts of the home care expenses. The child has used BiPAP® at night for more than four years now, and no serious complications have occurred.

From 1995 until now, there are 12 children on long-term ventilation discharged home under our supervision. Causes of ventilator dependence include congenital heart diseases, CCHS, SMA, diaphragmatic paralysis, congenital absence of hemidiaphragm, lung hypoplasia, poliomyelitis, sensorimotor neuropathy, and obstructive sleep apnea. Eight children have tracheostomies; four use noninvasive ventilation via nasal masks.

BiPAP® and CPAP units (Respironics Inc., Pittsburgh, Pennsylvania, USA) are the most common equipment we have been using. In our experience, these devices are effective in both noninvasive and invasive mechanical ventilation. They are durable and, more importantly, less expensive. In using these devices at home, no complications have occurred so far. Many of the children have shown remarkable improvement in their medical conditions and psychosocial development after discharge.

Home care for mechanically ventilated children will continue to grow in this region. Patient survival increases as a result of advanced technological life support in the hospital. More patients will survive acute life-threatening respiratory illnesses, thereby increasing the need for long-term ventilatory support. We hope that through our program this type of high technology home care will be made possible throughout the country in the future. ■

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INTERNATIONAL VENTILATOR USERS NETWORK (IVUN)

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Finding a Ventilator in Sri Lanka

M. Hafiz Issadeen

To be the parent of an 18-year-old son with Duchenne muscular dystrophy (DMD) can be an overwhelming experience, especially if you live in a third world country like Sri Lanka. Providing proper care for him is extremely frustrating.

I was a principal of a state school and had to retire prematurely to look after my son, Mohamed Irfan, as he became completely immobile and confined to his bed. I used to transfer him to his wheelchair for a few hours a day so that he could do some programming on my PC or be pushed into the front yard to see other children play cricket.

Last September, while seated in his wheelchair, Irfan's lips turned pale and he began to gasp for breath. I knew what it meant: his respiratory muscles were failing and he was slipping into the final phase of the disease. While attending the DMD parents' conferences in Rotterdam and Pittsburgh, I had listened to professors and clinicians speaking on the problem. I also remembered them saying that unless a ventilator is used to support the patient's respiration, his condition is bound to deteriorate.

Thus began my search for a ventilator. I was well aware of the problems that lay ahead of me – such equipment was not available for sale locally and the cost would be beyond our reach. But I could not wait. First, I sent a fax to a company named Pediatric Services of America (PSA) in Pittsburgh, which had displayed respiratory support equipment during the parents' conference. I also e-mailed Pat Furlong, president of The Parent Project for Muscular Dystrophy Research in the USA and to Elizabeth Vroom, president of The Parent Project in Holland. Both of these women have been of immense help to me.

Pat responded immediately by sending me details about the ventilator models available in the USA. She also contacted Dr. Jon Finder, a pulmonologist at the University of Pittsburgh to get his advice on the choice of ventilators. PSA promptly responded by giving me the particulars of a ventilator distributor for Respironics in India. When I found out that a BiPAP® S/T 30 would cost US$6700 plus Indian taxes, I was taken aback. "How can we find such a huge amount?" my wife lamented. She knew that our monthly income is only around US$150.

Then Elizabeth phoned from Holland wanting to know how far I had progressed in finding a ventilator. When I told her about my plight, she said, "Hafiz, don't worry about money! I will send you the details of my credit card and you can use it to purchase the machine. We are already late. So, try to get the machine immediately." I struggled to control my emotions and could not find words to thank her.

Meanwhile, Pat told me to contact Judith Fischer at IVUN. Judith also promptly offered help. She referred me to several people who could aid in finding a suitable ventilator for my son. Dr. Patrick Léger, a pulmonologist from France, also responded to my queries. I sent out e-mail after e-mail to people in Thailand, Hong Kong, Singapore, Bahrain, etc. to find out about the equipment available in those countries. Dr. Joshua Lim of Singapore, whom I had met in Pittsburgh, and Dr. Aroonwan Preutthipan of Thailand sent me valuable information and advice in this regard.

Soon I discovered that Breas Medical AB in Sweden manufactured high quality ventilators with a lower price tag. The marketing manager in charge of Breas products in Asia, Mr. Ola Erickson, wrote to me and said that he could hand carry a ventilator to Colombo if I confirmed the order and paid an advance to their local agent in Sri Lanka. But I had to choose a model before that.

From the information I had already gathered I decided on a bi-level positive pressure model called Breas PV 102. To check whether my choice was right, I wrote to Elwyn and Christina Mandley, Parent Project activists in Sweden. They forwarded my mail to a specialist in Stockholm, who wrote to me saying that the PV 102 model was suitable for my son, although the more expensive PV 401 model would be better in the long run. That was enough for me to decide in favor of the PV 102. I showed the green light to Mr. Erickson, and within days he was in Colombo with the machine.

I met Mr. Erickson at the local agent's office. He had already trained two technicians to handle the ventilator, which was the first of its kind in Sri Lanka. When I informed Elizabeth that I was satisfied with it, she remitted the money (US$3000), and at last the ventilator found its home.

The arrival of the ventilator made a big change in all of us. My mother and wife brightened up with hope. Above all, Irfan was highly elated. The depressive mood that had begun to hang over him was blown far away by the ventilator. After using the ventilator for the first time, he said, "It is like I am getting new life into my body. I could breathe so comfortably that I think I'm lucky." Yes, he is! But not all DMD children in this part of the world are as lucky as he is. ■

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Oxygen is NOT for Hypoventilation in Neuromuscular Disease

E.A. Oppenheimer, MD, FCCP

If progressive respiratory failure occurs in people with neuromuscular disease, an abnormal nocturnal oximetry study is often an early indication that hypoventilation is occurring. There are significant periods of decreased oxygen levels in the blood or hypoxemia during sleep when lying flat, in addition to decreases in vital capacity (VC), maximum inspiratory force (MIF), and maximum expiratory force (MEF). Decreased oxygen saturation (SaO_2) combined with increasing carbon dioxide (CO_2) retention or hypercapnia are the hallmarks of hypoventilation. This is sometimes called ventilatory pump failure, due to the weakened respiratory muscles.

Patients with neuromuscular diseases who are developing progressive respiratory failure due to respiratory muscle weakness will die unless mechanical ventilation is used. The rate of progression is often hard to predict. Some patients seem suddenly to experience life-threatening hypercapnic respiratory failure. They may not have been aware of gradually increasing symptoms and signs, particularly since they are often not physically active and are often not being regularly monitored with simple pulmonary function tests.

Administering oxygen does not provide assistance to the weakening respiratory muscles, but gives both the patient and the doctor the false impression that appropriate treatment is being provided. While in fact hypoventilation is mistaken for an oxygen transfer problem. Indeed, administering oxygen can mask the problem. Also there is a danger of causing respiratory depression by giving oxygen. Oxygen is **not** the treatment for hypoventilation. It will improve the SaO_2, but not the hypoventilation and may increase the danger of dying of sudden respiratory failure.

In hypercapnic respiratory failure due to hypoventilation, the SaO_2 falls due to the rise of the CO_2. The alveoli in the lungs (tiny gas exchange units) should clear most of the CO_2 out with each breath. Instead, with hypoventilation, CO_2 accumulates and thus there is decreased room in the alveoli for oxygen. When mechanical ventilation using room air is provided, it lowers the CO_2 in the alveoli, corrects the SaO_2, and rests the respiratory muscles. The ventilator should be adjusted to achieve a normal SaO_2, on room air. If oxygen is being administered, one cannot use noninvasive oximetry to tell whether enough assisted ventilation is being provided; repeated arterial blood gas specimens (ABGs) would be needed.

When there is respiratory failure in neuromuscular patients (ALS, post-polio, SMA, muscular dystrophy, etc.) who have no additional pulmonary disease that impairs oxygen transfer, the ventilator set-up is adjusted to:

– be comfortable for the patient;

– achieve SaO_2 of 95% or higher on room air (this can be measured with a finger-sensor oximeter);

– assist the patient to effectively cough and clear secretions;

– provide improved oral communication (if vocal communication is possible).

It has been common for people using noninvasive nasal ventilation (NPPV) with a bi-level positive pressure unit to use inadequate settings; frequently, they are not monitored with clinical evaluation and oximetry. The EPAP is often set too high – usually it should not be higher than 3-4 cm H_2O; the IPAP is set too low – usually it needs to be 12-16 cm H_2O and adjusted to achieve an oxygen saturation of 95% or higher.

Some situations may require administering oxygen, such as pneumonia due to infection or aspiration. If this occurs in patients with respiratory muscle weakness and hypoventilation, then it is important to provide both assisted ventilation and supplemental oxygen, and use ABGs to monitor them.

EDITOR'S NOTE: The IVUN office continually hears from people with post-polio or other neuromuscular diseases and conditions being inappropriately prescribed O_2 therapy. This anecdotal evidence (confirmed by the Mayo Clinic case series) supports the need for accurate information from the physicians most expert in the pulmonary aspects of neuromuscular disease to be disseminated more widely to alert people to the reasons why they should be wary of O_2 therapy.

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Additional Observations about Oxygen in Neuromuscular Disease

Anita Simonds, MD, FRCP, *Royal Brompton Hospital, London, England (a.simonds@rbh.nthames.nhs.uk)*

I agree completely with Dr. Oppenheimer that assisted ventilation is the appropriate therapy for alveolar hypoventilation. Apart from a limited number of situations such as pneumonia or lung fibrosis, oxygen therapy is usually inappropriate and may prove hazardous. Clearly, in an acute pneumonia O_2 therapy can be entrained into the ventilator system. Fortunately, in the United Kingdom, this message is getting across to healthcare workers and patients. There is still some inequity in providing noninvasive ventilation, but the situation is improving.

Lisa S. Krivickas, MD, *Instructor in PM&R, Harvard Medical School, Director of EMG, Spaulding Rehabilitation Hospital (LKrivickas@compuserve.com)*

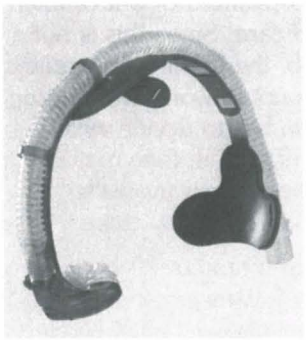
The analogy that I often use in regard to patients with respiratory failure from neuromuscular disease is that their lungs are like a deflated balloon which they are not strong enough to inflate. To inflate the balloon, mechanical assistance to force air into the balloon is needed. Blowing oxygen across the mouth of the balloon (the equivalent of using supplementary oxygen delivered by nasal cannula) will do nothing to inflate the balloon.

The case series published by the Mayo Clinic (see reference to Gay & Edmonds, 1995) demonstrates the dangers of administering as little as 1 to 2 L/min of nasal cannula oxygen. Patients with a variety of neuromuscular disorders experienced marked CO_2 retention; several became obtunded and required intubation or died when they were placed on 0.5 to 2 L of nasal cannula oxygen. ■

New Equipment, Masks, and Aids

Achieva™ is a new portable volume ventilator from Mallinckrodt Inc. that can also offer pressure support. The internal battery lasts about 4 hours, while the external battery lasts 20 hours. Weight is 32 lbs. Flow and/or pressure triggering matches the users' breathing efforts. Both internal dial-in PEEP and oxygen blending are available.

The Achieva™ comes in a series of models with pressure support offered in the Achieva™ PS and Achieva™ PSx (the PSx model also offers an internal modem for data storage). The Achieva series is somewhat more expensive than the LP10 (about $10,000 in the USA), with the high-end model almost $2,000 more. Contact Mallinckrodt Inc., Alternate Care Division, 2800 Northwest Boulevard, Minneapolis, MN (Minnesota) 55441-2625 (800-635-5267, press 2; www.mallinckrodt.com).



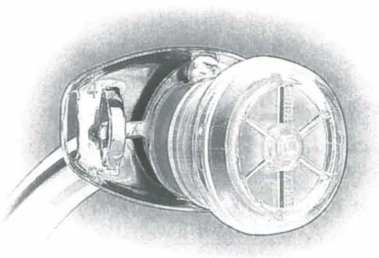
Breeze™ SleepGear™ is also new from Mallinckrodt. Designed with the ADAM nasal pillows, the SleepGear™ tubing goes up over the forehead and top of the head; it is held in place at the back of the head. No straps, easy to fit and wear, more freedom of movement while sleeping. Contact your local home health care dealer or Mallinckrodt Inc., Alternate Care Division, 2800 Northwest Boulevard, Minneapolis, MN (Minnesota) 55441-2625 (800-635-5267, press 2; www.mallinckrodt.com).

IQ™ nasal mask from SleepNet Corporation features a soft gel cushion and a pliable ring molded into the flexible shell which can be shaped quickly and easily to fit facial contours. It attaches easily to headgear, also manufactured by SleepNet. The IQ™ adjusts to the face, rather than the face adjusting to the mask. It is available (with a physician's prescription) from home health care dealers in the USA. Also available outside the USA. Contact SleepNet Corporation, 1050 Perimeter Road, Manchester, NH (New Hampshire) 03103 (800-742-3646; 603-624-1911; www.sleep-net.com).

LTV1000™ assessment by ventilator user Gary McPherson is a thoroughly detailed six-page report of his trial with the new laptop ventilator. Gary's assessment can be obtained by contacting IVUN, 4207 Lindell Boulevard, #110, Saint Louis, MO (Missouri) 63108-2915 (314-534-0475; 314-534-5070 fax; gini_intl@msn.com; www.post-polio.org/ivun.html).

TOPmask® is a new German semi-custom nasal mask from Weinmann GmbH & Co. Only available in Europe. Contact Weinmann GmbH & Co., P.O. Box 540268, D-22502 Hamburg, Germany (+49 40 54702 0; +49 40 54702 469 fax; www.weinmann.de).

PMV 2020 is new from Passy-Muir, Inc. A clear tracheostomy speaking valve, it comes with an adapter to be used with the Pilling Weck metal Jackson improved tracheostomy tube. The PMV 2020 can also be used with Bivona's nonfoam-filled cuffed tracheostomy tubes. Contact Passy-Muir, Inc., 4521 Campus Drive, Irvine, CA (California) 92612 (800-634-5397; 949-833-8255; www.passy-muir.com).



Ventilator-Dependent Child Abandoned: Reactions

In USA news at the end of 1999, there appeared the story of Richard and Dawn Kelso, wealthy parents of Steven Kelso, a 10-year-old with cerebral palsy and other conditions who used a ventilator. The Kelsos, allegedly unable to obtain nursing care over an extended period and caring for the child themselves, left him at the emergency room of a nearby children's hospital. They were charged with child abandonment and faced a criminal trial in March 2000, but admitted to abandoning their son and received one year of probation. Steven remains at the hospital.

The story brought a flood of letters to the editors of major newspapers and online magazine commentary, as well as fast and furious talk on the Internet. *IVUN News* readers who are parents of children with complex and multiple disabilities requiring tracheostomies and ventilators offer the following reactions:

From Joanne Kocourek, Illinois
(jskocour@midway.uchicago.edu)

It was with more than casual interest that I read the reports of Steven Kelso's abandonment. Caring for a medically fragile child (in our case *two* medically fragile children) 7 days a week, 24 hours a day with very limited support can lead one to become desperate to do something, anything to help or alleviate the situation. I seriously believe that people do not understand the nature of 24-hour care for technology-dependent children.

Our youngest daughter uses a ventilator 11 to 14 hours per day; she can experience intermittent, unpredictable decompensation at any time. We have physician-ordered, insurance-approved nursing care enabling us to work a regular workweek as well as sleep. Yet we frequently find that personnel is unavailable. Our oldest daughter has no supportive care ordered or authorized. The level of care she requires is custodial, and we have identified no third party payers which cover that level of care.

Many of our home care nurses maintain other jobs in order to receive benefits and make a decent living. They are not paid if they do not work the shift when our daughter is either hospitalized or out of town for medical care. Since this is not a full-time job, the home care workers can choose not to work. Our nursing agency then has to decide which cases are most vital; they may not have qualified nurses available to staff particular complex cases.

Many children require 24-hour care, and it means just that. A responsible individual must be alert and able to respond to medical emergencies such as apnea, hypoventilation, bradycardia, secretion management, equipment failure, or to initiate CPR. A friend or neighbor or relative cannot come over to casually watch your medically fragile child while you run errands or take a nap.

At the time Steven Kelso was born, his family was probably given the option of placing him in an extended care facility or group home. This family, much like ours, has gone to great lengths to provide a loving and safe home environment for their child. But when extremely stressed and likely overly tired, the Kelsos recognized that they needed help to provide the care their son required, and they sought that help in a way that seemed appropriate to them at the time. They received blame for bringing their son to a safe environment (one where he was well known) when his home care environment became unsafe because a home care agency failed to provide physician-ordered, payer-authorized coverage.

I have never done what this family chose to do, but I have come awfully close on many occasions. The lack of competent and available nursing support, authorization, and funding for services is extremely poor. There is nothing worse than being a sleep-deprived mother with no available support and being up around-the-clock to find that you nodded off during a potentially life-threatening monitor alarm. The child would be better off in the safety of a hospital, but then who makes the decision to admit the child and/or authorizes payment for the service?

People do not understand the desire to keep our children at home. All of the money in the world cannot necessarily supply individuals to do what many of us do around-the-clock, seven days a week.

From Nora Edgar, Michigan
(Neaaskmi@aol.com)

From what I have read, the Kelso family did not have enough nursing coverage over Christmas. Was this the first problem with nursing or was it ongoing? My husband and I went without nurses for three months, and for the last three years we have been minimally staffed. As foster parents, we had four other children, three with severe medical challenges, two were also total care. As a couple, we have not been away for four years. When we did get away, it was only overnight and we were so exhausted we slept most of time.

I do not feel any empathy for this family. They are reported to be a family in which the father runs a multi-million dollar company. If you are running a company that large, it seems that you know where to go, whom to talk with, and how to get things done. There are options for families, maybe none of them ideal, but they are available, at least to families with money: short or long-term institutionalization, guardianship, respite, live-in nursing care.

My main point is that a family does what they have to do to take care of their children. If we cannot, we need to search for the appropriate resources to help us. In my opinion (without knowing what the Kelsos had tried), dropping off their child at the hospital was not an appropriate option. A very young mother would be condemned and convicted for leaving her child with a friend or family member and not coming back.

Yes, raising a medically fragile child or any challenged child is difficult. But to drop the child off seems pretty drastic. On the other hand, sometimes parents get to the point where they can snap and are unable to handle things anymore. Perhaps leaving the child at the hospital was the Kelsos' way of protecting him, but then they have to face the consequences of their actions.

From Amy Menashe, Maryland
(imenashe@lankon.com)

I do not condone what this family did but in a twisted way I can understand. We all know the drill – not enough resources, not enough support, fights with doctors, nurses, and insurance. It is hard. I am tired of hearing that the Kelsos are rich – who cares? That does not exempt you from the hardships of raising a disabled child. And money can sometimes be a bigger burden because you cannot get access to certain resources.

This family could have done a lot worse to this child, so I guess the fact that they left him in a safe place is something to be thankful for. I would never leave my child, but there have been days when I thought I was going to break down and give up. Unlike this couple, I would never act on my feelings. This should be a lesson that there needs to be more support and resources for families with special needs children, no matter what your income is. ■

Noninvasive nasal ventilation in children with CCHS is the subject of a study underway by W. Gerald Teague, MD, Emery University, in collaboration with Mary Vanderlaan, PhD, founder of the CCHS Family Network. The study is surveying caregivers' reports on the usage and advantages/disadvantages of nasal ventilation. Preliminary analysis of 45 surveys is being conducted. For more information, check out www.cchsnetwork.org or e-mail VanderlaanM@hartwick.edu.

The 1999 Buyer's Guide from the *European Respiratory Journal* is now available online: www.ersj.org.uk. The compilation of respiratory products and companies also includes review articles, including one on noninvasive mechanical ventilation by Drs. N. Ambrosino and A. Simonds. To locate USA products and companies, the AARC's annual *Buyer's Guide of Cardiorespiratory Care Equipment and Supplies* is also available online at www.aarc.org.

"Across the Spectrum from Critical Care to Home Care" (the Seventh International Conference on Home Ventilation, March 14-17, 1999 Orlando, Florida) is available on a double CD-ROM (PC and Macintosh platform), for $150 (USD) from Waimea Technologie, Inc., 353, Saint-Nicolas, Suite 406, Montreal, Quebec H2Y 2P1, Canada (514-849-2422; 514-849-2272 fax; www.waimea-technology.com).

www.VentWorld.com is a Web site about ventilatory equipment, a kind of virtual equipment expo with product information, news, and events gathered from suppliers, professional societies, organizations, etc. Created by Amethyst Research, LLC, in Philadelphia.

www.pierrerobin.org is a new Web site started by Nancy Barry for parents with children who have Pierre Robin Syndrome or Sequence (PRS). PRS is a combination of birth defects which usually includes a small lower jaw, cleft palate, and a tendency for the tongue to "ball up" in the back of the mouth. Many of these children have breathing and feeding problems early in their lives. ■

CAMPS FOR VENTILATOR-ASSISTED CHILDREN

April 1-7. Ventilator-Assisted Children's Center (VACC) Camp, Miami. Contact Bela Florentin, VACC, 3200 S.W. 60th Court, Suite 203, Miami, FL (Florida) 33155-4076. 305-662-8380, ext. 4610.

June 1-6. Trail's Edge Camp, Mayville, Michigan. Contact Mary Dekeon, RRT, C.S. Mott Children's Hospital, University of Michigan, 200 East Hospital Drive, F3064, Box 0208, Ann Arbor, MI (Michigan) 48109. 734-763-2420.

June 12-16. Pennsylvania Vent Camp, Camp Victory, Millville, Pennsylvania. Contact Debra Randler or Michael Dettorre, DO, Pennsylvania Vent Camp, P.O. Box 850, Hershey, PA (Pennsylvania) 17033. 717-531-5337. (drandler@psghs.edu; www.collmed.psu.edu/pedsvent)

June 12-16. CHAMP Camp, Recreation Unlimited, Ashley, Ohio. Contact David Carter, RRT, CHAMP Camp, P.O. Box 40407, Indianapolis, IN (Indiana) 46240. 317-415-5530. (admin@champcamp.org; www.champcamp.org).

July 2-7. Camp Inspiration, Rocky Mountain Village, Empire, Colorado. Contact Monte Leidholm, RRT, The Children's Hospital, 1056 East 19th Avenue, Denver, CO (Colorado) 80218. 303-837-2502.

August 4-6. CHAMP Camp Adolescent Retreat. For ages 14-18. Timberpointe Outdoor Center, Hudson, Illinois. Contact David Carter, RRT, CHAMP Camp, P.O. Box 40407, Indianapolis, IN (Indiana) 46240. 317-415-5530. (admin@champcamp.org; www.champcamp.org).

September 1-4. SKIP Camp, Seashore Methodist Assembly, Biloxi, Mississippi. Contact Judy Abney, SKIP of Louisiana, 118 Ned Avenue, Slidell, LA (Louisiana) 70460. 504-649-0882.

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Calendar

2000

May 19-20. ALS Annual Leadership Conference. Crystal Gateway Marriott Hotel, Arlington, Virginia. Contact The ALS Association National Office, 800-782-4747; 818-880-9006 fax; mary@alsa-national.org; www.alsa.org.

June 8-10. Eighth International Post-Polio & Independent Living Conference. Saint Louis Marriott Pavilion Downtown, Saint Louis, Missouri. Contact GINI, 314-534-0475; 314-534-5070 fax; gini_intl@msn.com; www.post-polio.org/conf2000.html.

June 9-11. SMA Family Conference. Hilton Saint Louis Frontenac, Saint Louis, Missouri. Contact Families of SMA, 800-886-1762; 847-367-7623 fax; sma@interaccess.com; www.fsma.org.

June 23-24. The Parent Project Muscular Dystrophy Conference. Westin William Penn Hotel, Pittsburgh, Pennsylvania. Contact Patricia Furlong, The Parent Project, 513-424-7452; 513-425-9907 fax; Patfurlong@aol.com; www.parentdmd.org.

2001

March 7-9. Eighth International Conference on Home Mechanical Ventilation. Lyon, France. Journées Internationales de Ventilation à Domicile (JIVD), Hôpital de la Croix Rousse, Service de Réanimation Médicale et d'Assistance Respiratoire, 93, Grande Rue de la Croix Rousse, F-69317 Lyon Cedex 04, France (+33 4 78 39 08 43; +33 4 78 39 58 63 fax; BrigitteHautier_JIVD@compuserve.com).