

ON THE ROAD WITH THE NEWPORT HT50 VENTILATOR

Debbie Perlman (psalmsplus@aol.com, www.HealingPsalm.com)

Twenty-four years ago, at the age of 27 and with a husband and 5-month-old daughter, I was diagnosed with advanced Hodgkin's disease, a form of lymphatic cancer. The following years of surgery and chemotherapy, radiation treatments, side effects, and cancer recurrence left me physically disabled and oxygen dependent. A lung resection for recurrent cancer in 1988 decreased my vital capacity further. In addition to my respiratory problems, various treatments caused muscle wasting in my hips. I walk with a cane and use a manual wheelchair, pushed by someone else, for distance. After a year of continuous oxygen by nasal cannula, I began using a transtracheal oxygen catheter.

In early July 1996, my summer cold developed into pneumonia, complicated by a pleural effusion (a large accumulation of fluid) below my left lung. In the ICU, using a ventilator for the first time, my breathing was monitored and quantified by physicians, nurses, and respiratory therapists, while I was supported by the healing energies of family and friends.

Eventually, as my respiratory system continued to fail, a tracheotomy was performed (the surgeon enlarged the existing stoma for the transtracheal oxygen). Since the autumn of 1996, I have used a ventilator for about half the day, mostly for sleep and an afternoon nap,

but increasingly to help me perform such daily activities as showering and dressing.

I had been using an LP10 ventilator, a heavy and bulky machine. But we live in a tri-level house, and I became interested in a smaller ventilator that I could move between floors, knowing that my time using the ventilator would gradually increase.

Our daughter's marriage in September 2001 was the catalyst for the search for a small, portable ventilator, because her new in-laws live in Naples, Italy, and invited us to Italy to return the hospitality we showed them during the wedding.

I have always been a nervous traveler, and my husband Reid's anxiety during travel had grown as I became increasingly disabled. We had not traveled since December 1999, when two weeks in Florida with friends ended in an emergency hospitalization for respiratory failure due to a stress and infection-induced sodium imbalance.

If the idea of a three-hour plane ride sent me gasping and sweating into a panic attack, how could I manage to fly to Italy? I would never survive a 10- or 11-hour flight without being ventilated. I also knew that being able to relax and sleep on the airplane while using the ventilator would allay my anxiety.

My Internet research led me to the HT50 manufactured by

Newport Medical Instruments, Inc. (www.newportnmi.com). In addition to its small size and weight (about 15 lbs.), what impressed me the most was its internal battery that lasts for 10 hours. The HT50 recharges while it is running and plugged in, and can accommodate both American and European current. Through my home care provider and with my physician's consent and prescription, a trial with the HT50 was arranged. I took as deep a breath as I could, called my travel agent and purchased airline tickets to Italy.

"It's so cute!" I reacted when Dependicare's head of respiratory services, Luis, and Troy, an experienced respiratory therapist who had studied the HT50 manuals, brought the unit to my house. It is a wedge-shaped baby ventilator, small and lightweight enough for me to move around. It accommodates the disposable circuits my pulmonologist prefers and has a system for blending in oxygen. Troy familiarized me with the settings and alarms; they were easy to learn. The alarm is loud enough but not "screaming," and the alarm cancels immediately when the problem is fixed. The quiet noise the HT50 makes is more of a warbling sound, compared with the LP10's whoosh and groan.

I tried the HT50 while Troy monitored my oxygen saturation. It felt a little different from the

VENTILATOR USERS' PERSPECTIVES ON THE IMPORTANT ELEMENTS OF HEALTH-RELATED QUALITY OF LIFE: FINAL REPORT

Funded by The GINI Research Fund, Saint Louis, Missouri, USA

The final 115-page report on this qualitative study (www.post-polio.org/ivun) presents the perceptions of the health-related quality of life of 26 individuals living in the community (Toronto and Edmonton) with long-term use of home mechanical ventilation due to neuromuscular disability or traumatic injury.

"Since I was first ventilated I was determined to go on living my life the way I had been, and so I didn't really let it affect my lifestyle that much and in the long run, it really hasn't, other than the housing issues and the equipment and the attendants ..."

All participants use assisted ventilation for 12 to 24 hours a day via noninvasive modes or tracheostomy. Ages range from 23 to 66 years; 16 male and 10 female. Diagnoses include polio, muscular dystrophy, atrophy, spinal cord injury, ALS, transverse myelitis, and cerebral palsy. Years of ventilator use range from 2 to 53 years.

"I think that the biggest thing that keeps people with so-called disabilities disabled really is the focus on it. I could spend my entire day being disabled and everybody would support me to do that, but that's not much fun."

Mechanical ventilation is perceived as a positive benefit to independent living rather than the intrusive burden that the general public and health care providers assume it to be. Participants describe themselves as healthy and involved within

their communities in employment, volunteer work, homemaking, advocacy, and social recreational pursuits.

"My energy was back, I was renewed, it was wonderful. ... it was noisy because the air had to escape, but that didn't bother me because I was so glad to have this wonderful thing that was making me breathe."

Factors facilitating their perception of having a high quality of life are identified as personal support workers, friends, family, volunteers, assistive devices, assistance with activities of daily living, advocacy, workplace and educational accommodations, accessible supportive housing, income security, health management, and personal attitudes.

"We need time to sit down and talk to our doctors about our whole aspect, not just one, so that they understand all the various factors that impinge upon us and cause things like tiredness, so they've got a whole picture."

Barriers to achieving an optimum quality of life are identified as inadequate design of mechanical ventilation technology, lack of support from health care professionals, and suctioning issues. Those who require suctioning assistance are limited in their community involvement because of lack of support personnel to accompany them.

"... don't think of things in terms of barriers ... that's part of the problem; you can convince yourself that the wall is really there and it isn't. It's all about what's

possible and being good at communication and developing powerful ways of reaching people ... and people do break through what appear to be barriers."

Other frustrations, commonly expressed by persons with significant physical disability, are related to attitudes of the general public, accessibility, income, transportation, and the bureaucratic work involved in accessing and coordinating the multiple supports from programs on which they are dependent and of which they have little control.

"... the very services that are supposed to help you be more independent and get some autonomy are the ones that destroy it and make it impossible ..."

Recommendations for improving the quality of life of ventilator users include:

- ◆ improved home ventilation equipment and services with greater choice and flexibility;
- ◆ opportunities for involvement in equipment design;
- ◆ improved health care services through enhanced funding, coordination, and education of health care professionals;
- ◆ increased support for and availability of personal support workers, structured for the convenience of users rather than providers;
- ◆ public education about and respect for ventilator issues;
- ◆ improved accessibility to buildings, services, recreational opportunities, and travel;

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HOME MECHANICAL VENTILATION IN TAIWAN

Meng-Chih Lin, MD* (mengchih@adm.cgmh.org.tw)

Respiratory home care in Taiwan awaits further development. Due to cultural differences and the discrepancy between medical fees and health care insurance, it is more difficult for Chinese people to use mechanical ventilation at home after intensive care than it is for Europeans and North Americans.

There are more home ventilator users due to acute respiratory failure (discharged from acute care hospitals) than there are ventilator users due to chronic respiratory failure and prophylactic use.

The concept of a respiratory care team, first established at National Taiwan University in 1973, now has been accepted by most of the hospitals. In 1990, our team at the Chang Gung Memorial Hospital discharged our first home ventilator user, an individual with a high spinal cord injury, and he is still mechanically ventilated at home.

Hundreds of patients who were in stable condition after acute illness or trauma have been discharged from the hospital to home mechanical ventilation in the past several years. According to an unofficial investigation, 40-50 of these patients still live at home in Taiwan. Among them, 80% are adults, cared for by their siblings. Most of the pediatric patients are cared for by their parents. The great obstacles in caring for these patients are the deficiency of manpower and lack of financial support.

The respiratory home care companies have made great progress in recent years. They can provide equipment maintenance

and also some nursing and respiratory care. Our government provides only the respiratory equipment fee for rental of ventilators, oxygen concentrators, and suction machines (about \$780 USD per month). Families must pay nursing visit fees and respiratory maintenance fees themselves.

Two years ago in Taipei, the city government started to provide care during weekends because some of the families had difficulty in finding enough caregiver support. At present, there is no law which lists minimal requirements for home care company operators or which protects home caregivers.

Almost all of the home mechanical ventilation patients have tracheostomies and use Bear 33, PLV®-100, or LP6 positive pressure ventilators. Less than 5% use noninvasive mask ventilation with BiPAP® S. Patients with neuromuscular diseases comprise the largest group; the remainder have had chronic lung disease or spinal cord injuries.

One special group in Taiwan is unresponsive patients due to cerebrovascular accidents or head trauma. Though they have little life quality for themselves, their families wish to maintain their vital signs while bringing them home to avoid hospital infections.

The pediatric patients with enterovirus-induced encephalopathy and neuromuscular complications comprise a large percentage. They have raised more concern in recent years because pediatric patients are not enrolled in the home care health system.

A good long-term care system is necessary for a developed country. In Taiwan the government started a program to include all long-term mechanical ventilation patients. The Integrated Delivery System (IDS) includes acute care, sub-acute care, and long-term respiratory care. By enrolling patients who are ventilated in the intensive care units without any active infection for more than 21 days in a special unit or Respiratory Care Center (RCC),

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CHARCOT-MARIE-TOOTH: A "BREATH TAKING" REALITY

Susan Wheeler, BSW (cmt.today@sympatico.ca)

Charcot-Marie-Tooth (CMT), named after the three physicians who first described it, is a hereditary disorder of the peripheral nervous system. My experience with this disease has been longstanding. Initially, my late mother was told, as a child, that she had polio. Apparently this was not true and became painfully evident during the early development of two of her three children. One of the most difficult aspects of CMT during the early fifties was acquiring a true diagnosis.

For me, the progression of CMT has been gradual, consistent, and always unpredictable. My mother died at the age of 39, thereby limiting the awareness of what I might expect to encounter as I aged with this unusual disease. Several orthopedic surgeries and other modes of medical intervention helped to counteract and manage some of its neuromuscular effects. As was expected, my mobility, dexterity, and overall muscle strength steadily deteriorated, but to what degree this will continue is uncertain because individuals are affected differently, even those in the same family.

SUSAN WHEELER is editor of *CMT...today*, a new newsletter/magazine for people with CMT. She fills the gap caused by the retirement of Linda Crabtree, the founder of CMT International, which ceased publication of its newsletter in 2002 after 18 years. Linda's website (www.cmtnews.com) contains some of the best articles from the 103 issues of the *CMT Newsletter* published from 1984 through February 2002.

To my knowledge, breathing challenges were not correlated with CMT. Therefore, at the age of 27 when I began to experience what I now understand to be classic symptoms of hypoventilation (high CO₂ levels and low oxygen saturation), I looked for other causal factors in my lifestyle. For a period of seven years, I awoke each morning with a migraine headache that lasted as long as two hours. During the day I experienced waves of severe fatigue.

I diligently searched for relief and assistance from a variety of sources. I pursued both traditional and nontraditional medical alternatives, all to no avail. Living in Toronto, Canada, afforded me the opportunity to see highly qualified neurologists and other medical professionals, but an array of tests and numerous migraine medications brought no resolution or understanding about the cause of my distress.

After exhausting all possible options, I stopped looking for relief and instead learned to accept this high level of daily pain. I built a three-hour morning headache care program before going to work into my daily schedule, awaking at 5:00 a.m. to take a timed sequence of headache pain medicines thirty minutes apart.

Several years later, at the age of 37, I learned that I had a heart condition, Wolff-Parkinson-White syndrome. While in hospital it was discovered that my oxygen saturation levels were dangerously low. This finally led to the awareness that CMT had weakened my diaphragm muscles

and that assisted ventilation was necessary. I was immediately set up with BiPAP® S/T and nasal mask, supplemented with oxygen. Within three weeks of using this equipment, the morning headaches stopped, and I slowly began to improve, experiencing less daily fatigue.

Currently, I use BiPAP at night and sometimes during the day when I am fatigued. I cannot sleep at all without it. When I have dozed off while watching television, I awaken gasping and feeling smothered.

My oxygen saturation levels and blood gases are monitored to assess the BiPAP settings, and I have a sleep study at least once a year. The BiPAP settings were substantially increased last winter when I experienced the return of headaches and increased daytime fatigue. The inspiratory pressure is now at 18, after adjusting from 14 to 16 and then to 18, over two months. The expiratory pressure is now 6, up from 4.

After the latest sleep lab test, I was also started on a new medication, Mirapex – a drug for Parkinson's disease – that made an enormous difference in my overall health. I sleep more restfully, I wake up refreshed, the bouts of daily fatigue are almost nonexistent, and my general pain level associated with CMT (back, hips, hands) has significantly decreased.

Looking back, had I been referred to a respiratory specialist by any one of the many neurologists from whom I sought help, or had pulse oximeters been available then, many years of intense

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HOMEBOUND RESTRICTION EASED

Thanks to David Jayne and his National Coalition to Amend the Homebound Restriction (NCAHB), the Centers for Medicare & Medicaid Services (CMS) directed home health agencies and the contractors that pay home health claims to be more flexible in determining if a severely disabled individual is qualified as homebound (www.hhs.gov/news/press/2002pres/20020726d.html).

The instructions make clear that chronically disabled individuals who otherwise qualify as homebound should not lose home health services because they leave their homes infrequently for short periods of time for special occasions such as family reunions, graduations, or funerals. In some instances, home health agencies and Medicare payment contractors terminated home health benefits after a beneficiary attended a special event, even though the beneficiary otherwise continued to qualify as homebound.

The new language in the program manual for home health agencies expands the list of examples used to illustrate occasional absences from the home and notes that the list is still not all-inclusive. It adds the late stages of ALS and other neurodegenerative diseases to the list of examples of conditions that may indicate that the patient cannot leave the home. The determination whether a person is homebound is one that must be made over a period of time, not on a daily or weekly basis, so a few special trips outside the home would not be used to disqualify someone.

Before CMS issued the guidance, Tom Scully, Administrator of

CMS, met with David Jayne and others working to amend the law (see *IVUN News*, Summer 2002). Scully expressed concern that some Medicare beneficiaries are unjustly and wrongfully denied the home health benefit for so-called "homebound violations."

Scully also asked for the disability community's help in identifying Medicare beneficiaries who have had their home health services cut off because of an extremely harsh interpretation of the homebound restriction. If you or someone you know has been denied home health services for what may be a wrongful interpretation of the homebound rule, please contact Jayne (Djayne23@aol.com).

- ◆ Describe the circumstances in which home health services were discontinued because of an alleged "homebound violation."
- ◆ Explain your disability or chronic illness and why you need to continue to receive Medicare home health services.
- ◆ Include contact information (email, phone and mailing address) for yourself and your home health agency so CMS staff can follow up.

Alerting CMS to misapplications of the homebound rule will provide further evidence for Congress to amend the policy. "Clarifying" the policy is not enough.

Passage of the "The David Jayne Medicare Homebound Modernization Act of 2002" (S. 2848) is also critical. Please urge your U.S. Senators to cosponsor S. 2848. ■

For more information, visit www.amendhomeboundpolicy.homestead.com.

Potpourri

MDA Clinical-Research Chat on Respiratory-Ventilation Issues with E.A. Oppenheimer, MD. The transcript of Dr. Tony Oppenheimer's online chat, June 19, 2002, is available (www.mdaua.org/experts/trans.html). It contains a wealth of information about breathing and assisted ventilation for people with neuromuscular conditions, plus excellent references and resources.

Noninvasive Ventilation by John R. Bach, MD, is new and available from Hanley & Belfus, Philadelphia, Pennsylvania (800-962-1892, www.hanleyandbelfus.com). Publisher's quote: "This book is unique in presenting the use of entirely noninvasive management alternatives to eliminate respiratory morbidity and mortality and avoid the need to resort to tracheostomy for the majority of patients with lung or neuromuscular disease." ©2002, 600 pages, 200+ illustrations, ISBN 1-56053-549-0. \$39 USA; \$44 outside USA.

MiCASSA, the Medicaid Community-Based Attendant Services and Supports Act, is now H.R. 3612, with a growing list of sponsors.

This legislation brings Medicaid into accord with the Olmstead ruling of the U.S. Supreme Court, which forces States to end unnecessary institutionalization of people with disabilities who can remain at home with attendant services (www.adapt.org). ■

the hospital can reduce the cost and improve the quality of care.

Patients in the RCC receive intensive training in order to be weaned from mechanical ventilation. If weaning is not successful, these patients are transferred to a step-down unit or Respiratory Care Ward (RCW) for long-term respiratory care. If the family is willing, they can assume the responsibility and bring the individual home. Only 10% of the patients in the RCW have families who have considered doing that.

In general, home mechanical ventilation in Taiwan is still not popular and well accepted, nor is noninvasive application of mechanical ventilation. The major factor for this is physicians: they prefer a tracheostomy rather than a noninvasive mask. ■

*Lin, M.C., Huang, C.C., Lan, R.S., & Tsai, Y.H. (1996). Home mechanical ventilation: Investigation of 34 cases in Taiwan. *Chang Gung Med J*, 19, 42-9.

VENTILATOR USERS' PERSPECTIVES CONTINUED FROM PAGE 2

- ◆ less bureaucracy so that ventilator users can access needed services in a timely and appropriate manner. ■

*Research team included Dina Brooks, PhD, Assistant Professor, Department of Physical Therapy, University of Toronto; Mark Tonack, MA, Senior Research Officer, Toronto Rehabilitation Institute, Lyndhurst Centre; Audrey King, MA, Bloorview MacMillan Children's Centre (retired), Consumer Advocate, Ventilator User; Helen Simson, PhD (in progress); Maria Gould, MA, Interviewer and Project Coordinator.

INTERFACES AND EQUIPMENT

MASKS

7600 Series VMask is a full face mask, recently approved by FDA for use with CPAP/NPPV, available in five sizes from Hans Rudolph, Inc. (800-456-6695, www.rudolphkc.com).

The face piece and sealing flange are made of silicone in a new anatomically contoured design with ribbed support for a leak-free comfortable fit. The mask has an anti-asphyxia valve and CO₂ flush holes. Quick-release headgear is available in two sizes.

Oracle™, the new oral mask from Fisher & Paykel Healthcare (www.fphcare.com), has received an enthusiastic review from ventilator user and respiratory polio survivor Doug Martin who lives in Los Angeles. Doug uses mouth intermittent positive pressure ventilation (MIPPV) during the day with a mouthpiece and old LIFECARE PVV. He also is using the LTV800™ (Pulmonetic Systems, Inc., www.pulmonetic.com) on a trial basis and finds it very satisfactory.

Doug had trained himself to use MIPPV during the night (without a seal), finding nasal and facial masks claustrophobic and causing skin breakdowns. Diana Guth, RRT, Home Respiratory Care Sleep Solutions (diana@hrsleep.com), introduced him to the Oracle for night-time use. She secured the Oracle with a Puritan Bennett chinstrap because his cheeks inflate so much that the outside flap of the Oracle pops out.

The advantages of the Oracle for Doug are: comfortable fit, tight seal and less leakage, low maintenance, and sustained and consistent ventilation. Doug finds the Oracle a bit disconcerting upon awakening because he cannot call for his attendant or take a drink of water as he used to, but he expects that awakening with the Oracle will become second nature. Doug believes the Oracle is the simplest and best interface he has ever used.

BATTERIES

For external batteries to power ventilators, many people recommend and prefer MK Batteries for their long life: 7-9 hours (800-372-9253, www.mkbattery.com).

The Bemes Leg-Bat29 battery is often used with the TBird® Legacy (800-969-2363, www.bemes.com). ■

CHARCOT-MARIE-TOOTH: A "BREATH TAKING" REALITY CONTINUED FROM PAGE 4

pain and deterioration could have been avoided. In the neurologists' defense, I came to understand that CMT was not thought to affect the diaphragm in this manner. Nonetheless, a small percentage of people with CMT have breathing problems and need assisted ventilation. ■

Ed. Note: Karen Roth (Mahotah767@aol.com), who also has CMT, uses a PLV®-100 volume ventilator and custom nasal mask during the night. She was diagnosed with breathing problems in 1987.

LP10; the breaths seemed deeper to me, but I easily adapted. Naples seemed closer and more beautiful than ever.

A week before Reid and I were to leave for Italy, Reid had a heart attack, followed the next morning by coronary artery bypass graft surgery. The portability of the HT50 was immediately put to the test. In the eight days that followed, I took the HT50 with me to the hospital each morning so I could spend as much time as possible with Reid. A couple of times we even settled in for afternoon naps together, presenting I am sure, a confusing picture to hospital personnel. Just who was the patient?

Home at last, healing and healed, Reid has recovered well. I continue to appreciate the portability of the HT50 (our private insurance covers the HT50). I use it in the car on internal battery, although I have a cigarette lighter plug that can also power it.

We have planned a trip to Sanibel, Florida, and although I will not need it for such a short trip, the HT50 was approved by Delta and American Airlines for in-flight use, thanks to its gel cell battery. I expect the HT50 to provide good service as my ventilation need increases ... and if we someday fly to Naples. ■

IVUN Resource Directory 2002/2003 will be in print in October. The *Directory* includes experienced health professionals, ventilator users, manufacturers of ventilator equipment and aids, service and repair, and related organizations, associations, and foundations.

To obtain a printed copy, send a check payable to "GINI" for \$8 USA; \$10 Canada, Mexico, Overseas surface; or \$12 Overseas air (USD only), or provide your VISA, MasterCard, or Discover credit card number, expiration date, and name on card, to GINI, 4207 Lindell Blvd., #110, Saint Louis, MO 63108-2915 USA.

Also at www.post-polio.org/ivun.

Calendar

2002

- OCTOBER 5-8** American Association for Respiratory Care: **48th International Respiratory Congress.** Tampa Convention Center, Tampa, Florida. Contact AARC, 972-243-2272, www.aarc.org.
- NOVEMBER 2-7** American College of Chest Physicians. San Diego Convention Center, San Diego, California. Contact ACCP, 800-343-2227, www.chestnet.org.
- NOVEMBER 8** Continuing Education Conference for Respiratory Care: **Focus Mechanical Ventilation/Airway Clearance/COPD.** Oakland, California. Contact Mary Marchand, 800-426-4224, ext. 1506.
- DECEMBER 9** Continuing Education Conference for Respiratory Care: **Focus Mechanical Ventilation/Airway Clearance/COPD.** Dallas, Texas. Contact Mary Marchand, 800-426-4224, ext. 1506.

2003

- MARCH 31-APRIL 2** Children Who Are Medically Fragile or Technology Dependent: **Building Relationships, Respecting Diversity.** Loews Philadelphia Hotel, Philadelphia, Pennsylvania. Contact Ken-Crest Services, 215-844-4620, www.kencrest.org/medfrag/conf.html.
- JUNE 26-28** CCHS Family Network Conference. Caribe Royale Resort Suites, Orlando, Florida. Contact Mary Vanderlaan, 607-432-8872, www.cchsnetwork.org.
- OCTOBER 23-26** Ninth International Home Ventilation Conference. Caribe Royale Resort Suites, Orlando, Florida. Contact IVUN, 314-534-0475, www.post-polio.org/ivun.

Noninvasive Ventilation Alternatives in Neuromuscular Disease Featuring John R. Bach, MD

Sponsored by Pulmonetic Systems, Inc. and Advanced Respiratory

Supported by Newport Medical Instruments, Fisher & Paykel Healthcare, and Millennium Respiratory Services

In association with NIVnetwork.com, Respiratory Resources, and International Ventilator Users Network (IVUN)

Friday, November 1, 2002, 6:30 pm – 9:00 pm (optional)

Saturday, November 2, 2002, 8:00 am – 6:00 pm

San Diego, California, Mission Valley Church of the Nazarene (4750 Mission Gorge Pl.)

The conference is open to both ventilator users and their families and to respiratory therapists (up to 7 CEUs) and other health professionals interested in the benefits, equipment, and procedures of noninvasive ventilation. Limited individual respiratory assessments and private conferences with Dr. Bach will be available.

People with post-polio, ALS, and muscular dystrophy who do not yet need to use a ventilator are invited to view the equipment and masks and to speak with others who are using noninvasive ventilation. The laptop ventilators (LTV™ series) from Pulmonetic Systems, Inc., and the HT50 from Newport Medical Instruments will be exhibited.

Registration <i>before</i> October 23:	\$25 for ventilator users (family caregiver or/attendant free)
	\$25 for health professionals
	\$50 for respiratory therapists (includes CEUs)
Registration <i>on or after</i> October 23:	\$30 for ventilator users (family caregiver or/attendant free)
	\$30 for health professionals
	\$60 for respiratory therapists (includes CEUs)

To register ... 800-426-4224, ext. 1506 (Mary Marchand, Advanced Respiratory) or enroll@TheVest.com.

For detailed program information and directions ... 760-654-4005 or www.Nivnetwork.com/sandiego.

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IVUN NEWS

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