

LONG-TERM VENTILATION: THE JERUSALEM EXPERIENCE

Eliezer Be'eri, MD (eb_alyn@netvision.net.il)

Alyn Pediatric and Adolescent Rehabilitation Center in Jerusalem provides a full spectrum of rehabilitation services for children from all parts of Israel. (See *IVUN News*, Vol. 12, No. 4, Winter 1998.)

In January 2000, the independent Respiratory Rehabilitation Unit, dedicated to addressing the rehabilitation needs of ventilator-assisted children, opened. The 13-bed unit accepts patients up to 24 years of age. Most referrals come from the various neonatal or pediatric intensive care units around the country. The most common referring diagnoses are congenital myopathies, severe bronchopulmonary dysplasias, upper airway abnormalities necessitating tracheostomy, and post-traumatic cervical spine or head injuries.

Treatment goals for individual patients range from weaning (with subsequent decannulation) to initiation of long-term mechanical ventilation, fulltime or nocturnal, invasive or non-invasive.

One of the major problems that we encountered in the unit, somewhat to our surprise, was the phenomenon of parents becoming excessively dependent on the unit to the extent that discharge home was significantly delayed. This was due not to the child's medical condition but to the parents' fear of resuming sole and constant responsibility for a ventilator-assisted child, which seemed to be related to

a lack of self-confidence on the part of the parents and a mindset of chronic hospitalization. These factors were compounded by the limited amount of assistance that ventilated patients receive from their HMOs in Israel. (Adults using long-term ventilation have a better support infrastructure than children have. The HMOs manage home ventilation programs effectively in the major cities, but not in outlying areas.)

As a result, the parents arrived in our unit believing that a meaningful family life would be

we addressed the issue of discharge pro-actively. We established a protocol that the topic of discharge home would be raised with all families within two weeks of admission. A timeline would be set, with a realistic target date for discharge. Parents would be encouraged to take the first steps towards discharge, usually by filling out forms requesting assistance from various bureaucracies, long before the child was ready to leave.

Most importantly, we ensured that the parents and child would leave the hospital briefly – to



Dalia, a young girl with arthrogriposis and hypoplastic lungs, feeds the elephant.

impossible to establish at home with their child. As the child gradually responded to rehabilitation therapy and improved, the parents' fear of discharge home, somewhat paradoxically, became even worse: "If we leave now, our child's progress will stop or be lost."

To break this cycle and to facilitate the process of going home,

visit a park or shopping mall or just walk around the neighborhood – as soon as possible after admission and regularly thereafter.

In April 2002, all of the children in the unit, accompanied by their parents, siblings, and medical staff, visited the local zoo. Not only was the outing great fun for the children, but it was

also an eye-opener for the parents. They were having a family outing and enjoying it! Once the mold of passivity induced by chronic hospitalization had been broken, we found that parents advocated for discharge home for their children far more actively and effectively. They became pro-active members of the rehabilitation team.

In addition to the Respiratory Rehabilitation Unit, Alyn also houses a 12-bed residential wing for long-term ventilator users. These people, now between 15-40 years of age, had been admitted to Alyn in the years prior to the development of a home ventilation program in Jerusalem.

They continue to live in the residential wing due to lack of an appropriate home care setting.

Most have been diagnosed with Duchenne muscular dystrophy and all use 24-hour mechanical ventilatory support via tracheostomy. They are fully mobile, with LP10 ventilators mounted on their wheelchairs, and travel outside of Alyn daily for work, studies, recreation, etc.

The mean period for using assisted ventilation by this group is eight years, with the oldest member (age 40) using full mechanical ventilation for the last 21 years. At 18 years of age, this patient decided to commence mechanical ventilation, *against* the will of his parents. Six months ago he completed a 10-day sightseeing tour of France, a longstanding ambition of his. A production team from a local film school produced a TV documentary of his

travels, which shows how he attempted to use the Paris Metro – unsuccessfully – despite their claim of wheelchair accessibility.

A striking characteristic of this group is their above average intelligence. This observation has led us to ask, “Is high IQ a predictor of a positive long-term outcome for home mechanical ventilation in people with Duchenne muscular dystrophy?”

The third arm of the respiratory rehabilitation service at Alyn is the Respiratory Rehabilitation Outpatient Clinic. The clinic follows 150 patients with progressive neuromuscular disease, particularly Duchenne muscular dystrophy, and offers both invasive and noninvasive long-term ventilation protocols, depending on individual preferences and suitability for each patient.

In the clinic, we monitor lung function tests, capnography, oxygen saturation, and sleep studies in order to guide patients through a program of respiratory exercises, mechanical in-exsufflations, assisted coughing, and mechanical ventilatory support via facemask or mouthpiece.

Unfortunately, the CoughAssist™ is not recognized as part of a comprehensive long-term mechanical ventilation protocol by the HMOs, and many patients are unable to afford it. To remedy this, we have developed a less expensive in-exsufflator of our own by combining a standard ventilator (which patients *do* receive from the HMO) with a household vacuum cleaner. Initial clinical trials of the device demonstrate its effectiveness, and the device is patent-pending. ■

Children Who Are Medically Fragile or Technology Dependent: Building Relationships, Respecting Diversity

March 31 – April 2, 2003

Loews Philadelphia Hotel, Philadelphia, Pennsylvania

Sponsored by Ken-Crest Services, in collaboration with the Philadelphia Department of Human Services

Held every two years, this fifth national conference brings together more than 400 individuals from health care, child welfare, education, law, and government, along with family members. They discuss medical, legal, ethical, social, educational, and financial issues and learn about innovations in care.

“Building Relationships, Respecting Diversity,” the conference theme, reflects how the diversity of culture and abilities among children who are technology dependent is essential to their care, support, and treatment as well as the building of successful relationships among parents/caregivers, professionals, governments, institutions, and agencies.

To submit a proposal for a presentation, apply online at www.kencrest.org/medfrag/conf.html. For updated conference information, contact Ken-Crest, 215-844-4620.

FROM NEGATIVE TO POSITIVE

Lewis Gumerman, MD (gumerman+@pitt.edu)

I finally made the transition to positive pressure (volume ventilator with a mouthpiece during the day and face mask at night) in the winter of 2000, but I had been warned about the ultimate need to do that as long ago as 1989. That's when Geoffrey Spencer, OBE, MB, FFARCS, told me that, as my vital capacity decreased and I aged, the chest cuirass would prove inadequate. He recommended intermittent mouth positive pressure ventilation and introduced me to the PLV®-100. But, as a respiratory polio survivor, I had been using the negative pressure system since the late 1950s after I moved out of the iron lung, and change in procedures has never come easy to me.

When Mark Sanders, MD, my pulmonologist in Pittsburgh, suggested in the early '90s, gently at first but gradually more forcefully, that I switch to positive pressure with a face mask, there were a number of false starts. The process was complicated by several factors.

I could not manage the mask alone. Someone would have to be available all during the night to make adjustments should they be necessary, and in the beginning those proved very necessary. My late wife, Ruth, was an anxious sleeper, so I was reluctant to have someone walking in and out of the bedroom during the night, responding to leaky mask problems. Not convinced that the change was going to work, I did not, or would not, buy a humidifier at first, so I could not use nasal ventilation for more than an

hour or so before my nose became stuffed up.

With these excuses, I managed to put off a serious run at this problem.

Then Ruth became ill with a malignancy and chemotherapy that made nighttime interruptions out of the question. I told Dr. Sanders we would have to revisit the issue later. Meanwhile, periodic annual overnight oximetry both at home and in the sleep lab showed worrisome periods of oxygen desaturation, and the headaches were fierce.

After Ruth died in the fall of 1997, I finally got serious and bought a humidifier. Dr. Sanders ordered a steroid nasal spray for use at bedtime. By this time I had arranged to have my daytime helper sleep over to lessen my dependence on my grown daughter. Thus, all my excuses were invalidated.

Oddly, the motivation to make a determined push came on a trip to California to visit my son and daughter-in-law whose help made all the difference. The new system worked from day one. I have been very satisfied with the result, although mask seal (until now Respironics' recently discontinued Gold Seal®) remains difficult at times.

At first, following what is probably a common mistake of beginners, I thought "tighter is better." It was only a matter of days before the skin and cartilage of my nose demonstrated the fallacy of that approach. Every time frustration with my most common leak, high up on the bridge of the nose, leads me to tighten up on the top straps,

I am reminded the next morning of the truth of "loose as possible is best." Sometimes I have periods where the mask fit is impossible. (Suggestions from other mask wearers would be appreciated.)

I have three PLV®-100 ventilators: one by my bed; one that mainly stays in my van for travel; and one in the room where I spend most of my time during the day. I deactivated the low pressure alarms (signing off on that with Respironics' lawyers) on all but the one I use during the night. ■

International Ventilator Users Network

IVUN News (ISSN 1066-534X)
Summer 2002 ■ Vol. 16, No. 2

IVUN News links ventilator users with each other and with health care professionals interested in mechanical ventilation and home care.
ISSUED IN MARCH, JUNE, SEPTEMBER, DECEMBER

EDITOR: Judith Raymond Fischer
GRAPHIC DESIGN: Sheryl R. Prater

International Ventilator Users Network (IVUN)

Coordinated by Gazette International Networking Institute (GINI)
4207 Lindell Boulevard, #110
Saint Louis, MO 63108-2915 USA
314-534-0475 ■ 314-534-5070 fax
gini_intl@msn.com

www.post-polio.org/ivun

Annual Subscription (US dollars only)
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DAVID JAYNE GOES TO WASHINGTON

David Jayne and the National Coalition to Amend the Homebound Restriction (NCAHB) traveled to Washington, DC, in May to lobby for passage of legislation (HR 1390 and SB 2085) that would remove the homebound restriction and be included in the Medicare bill later this year. It is URGENT that you write your Senators in support of SB 2085 and your Representative in support of HR 1490. For more information: www.amendhomeboundpolicy.homestead.com or djayne23@aol.com.

Excerpts from David Jayne's press conference, Washington, DC, May 16, 2002:

"Before I begin, I need to express my tremendous gratitude to several individuals. Congressman Markey and Congressman Smith, thank you for having the courage to right a wrong in the Medicare system by introducing the Homebound Clarification Act of 2001 (HR 1490). I want to thank Senator Collins and Senator Cleland for introducing the Home Health Modernization Act of 2002 (SB 2085).

"... Fourteen years ago, I was 27 years old, newly married, with a promising career ahead of me when I noticed a persistent twitch in my left arm. Several months later, seated in a small examination room, I heard the doctor say in a matter of fact way, 'It is ALS or you might know it as Lou Gehrig's disease.' In total disbelief I asked, 'How long?' Without hesitation, the doctor said, 'Three to five years.' That was the beginning of an ongoing journey of many changes and challenges.

"As the years passed, and my body was consumed by ALS, I lost the ability to walk and this wheelchair replaced my legs. I lost the ability to eat and a feeding tube was placed in my stomach to provide nutrition.

I lost the ability to speak and this computer replaced my voice. Finally, I lost the ability to take a life-giving breath, so now this ventilator sustains life ... It requires two people two hours to get me out of bed, showered, and dressed for the day.

"Because I require skilled nursing care to change my tracheostomy and feeding tubes, Medicare has paid for a nurse to come to my home twice a month since 1997. Only because I need skilled nursing care do I qualify for a home health aide to assist with my morning routine.

"In the fall of 2000, the *Atlanta Journal-Constitution* ran an article about my life and activities, such as my involvement in ALS fundraisers and traveling with a college buddy to watch my beloved Georgia Bulldogs play the University of Florida. This was the first time in over three years I had left my home overnight except for hospital stays. The trip was difficult, but wonderful. I had not felt that alive in years ...

"Three days after the article appeared, I was discharged by my home health company for homebound violations. Congressman Mac Collins came to my aid and services were restored pending an appeal, but at the cost of being under house arrest

again. For this trip to Washington, I contacted the CEO of my home health company and informed him of my travel plans. I do not know my fate when I return.

"I was extremely fortunate that my situation played out on the front page of the newspaper. Since my story has gone public, I have received thousands of emails. Many of the individuals who contacted me shared similar experiences with Medicare's homebound restriction. Soon thereafter, I founded The National Coalition to Amend the Medicare Homebound Restriction and began a petition drive that has collected more than 17,000 signatures ...

"I am not advocating expansion of the Medicare system, and the language in HR 1490 and SB 2085, is not either. I am only asking that the homebound restriction follow in the spirit of the ADA, the Olmstead Decision, Ticket to Work, and President Bush's New Freedom Initiative. HR 1490 and SB 2085 will not convert the Medicare home health benefit from a short-term, acute care benefit into a long-term, chronic care benefit. If we eliminate the part of the homebound definition that refers to absences for short duration, does that leave a definition that can be administered?

The homebound restriction still would retain the requirement that leaving the home requires a considerable and taxing effort. The proposed modification would simply prevent patients with severe disabilities from facing the choice of being imprisoned in their homes or losing their Medicare coverage." ■

CONGESTIVE HEART FAILURE, OSA, AND BiPAP

Fred Schroader (fred_schroader@yahoo.com)

I was diagnosed with obstructive sleep apnea in July 1999. I had just begun showing signs of congestive heart failure. I am overweight and that was one of the reasons my doctor suspected that I might have apnea. I did not snore, but did become tired during the daytime.

When I was tested for sleep apnea, my oxygen saturation was 79%. I had premature ventricular contractions (PVCs) of 17 per minute, and my heart started to enlarge. I began using bi-level positive airway pressure (BiPAP) immediately and 100 mg of Coreg daily. BiPAP was prescribed instead of conventional CPAP because, after two sleep tests at a local hospital, it was determined that I was not able to exhale against the airflow of CPAP.

After using BiPAP for three months, the PVCs decreased, and my energy level increased dramatically. The physicians were amazed at my sudden turnaround.

I use the Tranquility® BiPAP with the Simplicity™ nasal mask (Respironics, Inc.). I went through a couple of masks before settling on the Simplicity. With the other masks, I experienced soreness around the bridge and on both sides of my nose. The only way I found relief was to place band-aids over the affected areas.

Then I tried the Simplicity™ and, because it was a nasal mask, I felt more comfortable with it than with the full-face masks. One night I forgot the band-aids, and the next morning I was pleasantly surprised to find I had no marks or soreness around my nose.

It took me about 10 days after I first started using the equipment to be able to sleep through the night. Another benefit is that I do not need to get up in the middle of the night to urinate.

I experienced dry mouth at first, but found that a humidifier provided no relief. I decided to keep a piece of hard candy in my mouth to keep it lubricated.

It did keep my mouth lubricated, but, by morning, my mouth felt gummy from the sugar in the candy. Then I tried a piece of Dots® made by Tootsie, which is more like a hard gumdrop. It works very well; in the morning, only a trace of sweetness remains.

My physician advises me that if I lose 100 pounds I might not need to use the equipment, but I am accustomed to having its soothing sound lull me to sleep. ■

Who's Right, Whose Right? Seeking Answers and Dignity in the Debate Over the Right to Die

Edited by Robert C. Horn, III

Who's Right, Whose Right? (2001) takes an objective look at the major issues surrounding an individual's right to choose life or death. It includes interviews with people facing terminal conditions and commentaries by physicians and ethicists on both sides of the right to die issue, including C. Everett Koop, MD, and Derek Humphry. The hardcover book, published by DC Press, is available from Barnes & Noble and amazon.com for \$24.95.

Bob Horn, ventilator user since 1991 due to ALS, is a former professor of political science at CSU-Northridge. His first book was titled *How Will they Know If I'm Dead? Transcending Disability and Terminal Illness*.

SAVE THE DATE!

Ninth International Conference on Home Ventilation "Noninvasive Ventilation: From ICU to Home"

OCTOBER 23-26, 2003
CARIBE ROYALE RESORT SUITES
ORLANDO, FLORIDA

Sponsored by the American College of Chest Physicians (ACCP) in conjunction with IVUN, JIVD, and National Jewish Medical and Research Center

Co-chairs Barry Make, MD, and Nicholas Hill, MD

A unique gathering of the expert physicians, nurses, and respiratory therapists in home ventilation, plus long-term ventilator users and ventilatory equipment manufacturers. If you missed this conference in Orlando in 1999, you have another chance.

Topics include noninvasive ventilation in acute care; long-term ventilation at home; ethical issues; sleep and breathing in neuromuscular disease; reimbursement issues; coughing; swallowing; and, of course, hands-on with masks and other interfaces.

Program and registration information will be available later on IVUN's site (www.post-polio.org/ivun) and ACCP's (www.chestnet.org).

Direct Relief International, a nonprofit organization based in a warehouse at the Santa Barbara Municipal Airport in California, shipped 951,000 pounds of donated medical supplies and equipment to more than 60 developing countries in 2001. Unfortunately, DRI did not ship any ventilators. According to Clint McColpin, BioMedical Manager, "We have so many requests that I could send hundreds if I had them." To donate ventilators, contact Clint at DRI (805-964-4767, www.directrelief.org).

Old Respiratory Equipment. A fascinating exhibit of old respiratory equipment and ventilators was on display at the Focus Respiratory Care Conference in Saint Louis in April. John Weisleder, RRT,

collects, organizes, and houses the exhibit (although it is not on display there) at Westchester Medical Center in Valhalla, New York. Weisleder would like to hear from anyone who has an "antique" that he might not already have in his collection (914-493-1189, weislederj@wcmc.com).

Look Beyond This Cover: The Bryan Pratt Autobiography. Bryan Pratt is a 26-year-old ventilator user with a severe form of muscular dystrophy who formed the nonprofit organization, Disability Outreach Foundation. Current goals of the foundation include helping sponsor the Illinois High School Association clinics and camps to ensure that wheelchair basketball will become a high school varsity sport in the state of Illinois (a

first in the nation) and providing annual scholarships to nursing students at the University of Illinois who assist people with disabilities in a non-institutional setting. All proceeds from the sale of the book go directly to Disability Outreach Foundation. The book can be ordered online (www.disabilityoutreach.org) or by mailing \$14 to Disability Outreach Foundation, P.O. Box 771, Arlington Heights, IL (Illinois) 60006.

Letters of Medical Necessity. John Bach, MD, has posted many sample letters on his site (www.DoctorBach.com) that help justify prescriptions for ventilatory equipment and aids, such as a volume ventilator, oximeter, and CoughAssist™. ■

MEDICAID AND PEOPLE WITH DISABILITIES: LIVING IN THE COMMUNITY

In May 2002, Health and Human Services (HHS) Secretary Tommy Thompson unveiled two new waiver templates that will help states better use the Medicaid program to enable people with disabilities to choose services in their own homes and communities.

The new "Independence Plus" waiver templates will give states tools to create programs that will allow people with disabilities and their families to decide how best to plan, obtain, and sustain community-based services, placing control in the hands of the people using the services. HHS recognizes the essential role of the family or individual in planning for and purchasing health

care services while, in many cases, delaying placing the individual in an institution or other high-cost out-of-home facility.

The electronic templates will provide guidance to states on how to develop these programs within existing federal requirements using a streamlined application process, which will ultimately result in faster federal approval of state proposals. Similar programs have been shown to promote cost-effective and flexible solutions for care while meeting the individual needs of people receiving services.

The templates were developed by the Centers for Medicare & Medicaid Services (CMS) – www.cms.hhs.gov.

HHS also announced a new Web-based resource to provide states and the public with information on available technical assistance related to community-integration issues. The "Compendium of HHS Technical Assistance Activities Related to the Administration's Community-Integration Initiative" provides one-stop-shopping for information related to the Medicaid program, family caregivers, employment supports for people with disabilities, promoting consumer-driven services and more. It is available at <http://aspe.hhs.gov/daltcp/reports/Citarpt.htm> and will be updated regularly. ■

NEW INTERFACES

In the USA, a physician's prescription is necessary to buy a mask or other type of interface, even when an individual wants to purchase one without going through an insurance company. Contact your local home health dealer or the manufacturers directly.

ComfortSelect™ is a new nasal mask from Respironics (800-345-6443, www.respironics.com). It features a dual-layer cushion and adjustable forehead bracket, and is available in small, medium, and small/wide. The Contour Deluxe™ nasal mask is being phased out.

MiniMe™ is the smallest nasal mask offered by SleepNet Corporation (800-742-3646, www.sleep-net.com). It features a soft gel cushion and is adjustable. A variety of headgear styles and sizes are also available.

Nasal Aire™, a low-profile interface that was first invented and marketed by Nasal Aire Technologies, Inc., in Waycross, Georgia, has been reintroduced by InnoMed Technologies in Boca Raton, Florida. Nasal Aire™ is a nosepiece with two silicone inserts that fit in the nostrils. The nosepiece is attached to tubing that can be worn over the ears, much like an oxygen cannula. No headgear or straps or skin problems on the nose. InnoMed (800-200-9842, www.innomedinc.com).

DeVilbiss Serenity™ Plus nasal mask from Sunrise Medical (800-338-1988, www.sunrisemedical.com) combines improved silicone technology with an adjustable frame and snap-in forehead

rest. Available in standard and shallow sizes.

Advantage™ from Tiara Medical Systems, Inc. (800-582-7458, www.tiaramed.com) is a small nasal mask that features a triple cushion seal and adjustable forehead cushion.

Oracle, a new oral mouthpiece mask from Fisher & Paykel Healthcare, can be used with both CPAP and bi-level units. The SoftSeal and SnapFlap™ combination ensures that there are no leaks. There are no straps or headgear to adjust, nor nasal problems. Contact Fisher & Paykel (800-446-3908, www.fphcare.com).

Diana Guth, RRT, and respiratory home care company owner in Los Angeles, tested the Oracle herself during a recent sleep medicine conference. She plans to evaluate it in a future *IVUN News*.

EQUIPMENT NEWS

KnightStar® 330, Puritan Bennett's newest bilevel positive pressure airway unit, has finally won FDA approval. Weighing only 2.7 lbs., it offers up to 30 cm H₂O pressure, leak compensation, complete alarm settings, and optional battery backup. Contact Puritan Bennett (800-635-5267, www.mallinckrodt.com).

Pulmonetic Systems, Inc. announces a new address effective July 1, 2002: 17400 Medina Road, Suite 100, Minneapolis, MN (Minnesota) 55447 (800-754-1914, 763-398-8300, 763-398-8400 fax, www.pulmonetic.com). ■

JOURNAL ARTICLES

Winslow, C., Bode, R.K., Felton, D., Chen, D., & Meyer, P.R. (2002). Impact of respiratory complications on length of stay and hospital costs in acute cervical spine injury. *Chest*, 121, 1548-1554.

Yasuma, F., Kato, T., Matsuoka, Y., et al. (2001). Row-a-boat phenomenon: Respiratory compensation in advanced Duchenne muscular dystrophy. *Chest*, 119, 1836-1839.

Lumeng, J.C., Warschausky, S.A., Nelson, V.S., & Augenstein, K. (2001). The quality of life of ventilator-assisted children. *Pediatric Rehabilitation*, 4(1), 21-27.

Newsom-Davis, I.C., Lyall, R.A., Leigh, P.N., Moxham, J., & Goldstein, L.H. (2001). The effect of non-invasive positive pressure ventilation (NIPPV) on cognitive function in amyotrophic lateral sclerosis (ALS): A prospective study. *Journal of Neurology and Neurosurgical Psychiatry*, October, 71(4), 482-487.

Schönhofer, B., Von Sydow, K., Bucher, T., Nietsch, M., Suchi, S., Köhler, D., & Jones, P.W. (2001). Sexuality in patients with noninvasive mechanical ventilation due to chronic respiratory failure. *American Journal of Respiratory and Critical Care Medicine*, November, 164(9), 1612-1617. ■

Calendar

2002

JULY 27

Continuing Education Conference for Respiratory Care: Mechanical Ventilation and Airway Clearance. St. Luke's Roosevelt Hospital Center, New York, New York. Contact Barbara Rogers, Respiratory Resources, Inc., 212-666-2210, breathezy@aol.com.

SEPTEMBER 3-5

American Association of Spinal Cord Injury Nurses. Riviera Hotel and Casino, Las Vegas, Nevada. Contact AASCIN, Sara Lerman, MPH, 718-803-3782, ext. 324, www.aascin.org.

SEPTEMBER 14-18

European Respiratory Society. Stockholm, Sweden. Contact ERS, www.ersnet.org.

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.

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.

OCTOBER 23-26

Ninth International Home Ventilation Conference. Caribe Royale Resort Suites, Orlando, Florida. Contact IVUN, 314-534-0475, www.post-polio.org/ivun.

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SUMMER 2002 ■ VOL. 16, No. 2

IVUN NEWS