International Ventilators Users Network

I.V.U.N. NEWS

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International Ventilator Users Network (I.V.U.N.)

links ventilator users with each other and with health care professionals interested in mechanical ventilation.

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IN MEMORIAM: GINI LAURIE, 1913-1989

Virginia Grace Wilson Laurie, or Gini, as she was known throughout the world, died of cancer on June 28, 1989, at the age of 76.

Named after two sisters who died during a polio epidemic in St. Louis, Gini was born on June 10, 1913. She grew up loving and advocating for a brother severely disabled by polio, and often called polio the motif of her life. When her husband, Joseph Scott Laurie III or "Papa Joe" as he was known, was transferred to Cleveland in the late 1940s, it was only natural for Gini to volunteer at the Toomey Respiratory Center during the polio epidemics of the 1950s.

Gini started the *Toomey j Gazette* (later to become the *Rehabilitation Gazette*) in 1958 to help polio survivors keep in touch with each other. The small mimeographed newsletter evolved into an international journal of independent living by people with disabilities. James Thompson, ventilator user and longtime *Gazette* reader says, "Her persistent labor in our behalf and first-hand accounts of other survivors in the *Gazette* have been both stimulus and sustenance."

Gini was the catalyst for the international conferences on the late effects of polio and was the force behind the publication of the *Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors*, referred to as the "bible" on post-polio problems.

Gini has been called the glue that held polio survivors togethers.

As archivist for the independent living movement, Gini's unparalleled collection of books, papers, and letters on the subject attracted rehabilitation professionals, scholars, and the leaders of the independent living movement. Visitors from around the world came to St. Louis to use the library and to interview Gini.

In her later years, Gini travelled widely as unofficial ambassador for all people with a disability, speaking about the history of the American independent living movement.

In 1983, the *Gazette* reorganized as Gazette International Networking Institute (G.I.N.I.) and is the umbrella organization for the *Gazette*, the International Polio Network, and the International Ventilator Users Network. Pledging to continue her work, the G.I.N.I. Board of Directors established the Gini Laurie Endowment

Gini was a motivator for everyone, demanding that each individual, with a disability or without, live life to its fullest. She believed in the dignity of each individual and believed that, as she often said, "Peopleness is the only thing that matters," a credo evident in the pages of her many publications, speeches, conferences, and especially in her way of life.

Ave atque Vale!



MUSINGS: ON INDEPENDENCE

by Karan McKibben, Ph.D.

Offhand, independent seems to be an odd word to use in describing the life style of an individual with a physical disability. Especially for those individuals who are more severely disabled, fate seems to have put immutable limits on autonomy. After all, how independent can one be if one depends on the vagaries of various mechanical devices for moving about. eating, even breathing. A thud in one's ventilator, a thumbtack in one's wheelchair tire, or a clipping screw in one's adaptive device can put a crashing halt to all autonomous activities, and one is put "on hold," so to speak, while a repairperson is located and cajoled into servicing the essential device today, not next week.

Even more detrimental to a sense of independence is the unavoidable dependency on other persons for such basic needs as getting out of bed in the morning, getting dressed, and getting to the places one chooses to go. When plans for the day seem determined primarily by the availability of attendants and the peculiarities of their work habits, one begins to suspect that self-determination is an illusion, at least in respect to oneself.

One is certain it is an illusion with the discovery that one's dependency extends also to society at large and that it is necessary to rely upon governmental programs for the resources needed to hire attendants, to obtain and maintain medical equipment and adaptive devices, and often also to pay the rent and buy food because the nature of the disability has severely

limited employment. In dealing with the bureaucracy, survival often seems to depend on conforming to the outdated stereotype of individuals with a disability as invalids needing protection, not self-determination.

Strangely enough, though, inherent in the very complexity and extent of this apparent dependency lies the key to self-determination. Because no one person or even institution can or ought to respond to the multifarious needs of people with a disability, the individual soon turns to a wide variety of agencies, institutions, businesses, schools, etc. Although some might view the decision to become dependent on the many instead of one as self-defeating, this decision dissipates the burden of responsibility and decreases the sense of dependency. With the realization that failure to respond to any one person or institution is merely an inconvenience rather than a catastrophe comes a growing confidence in one's own viability.

Moreover, by dispersing their dependency over a complex network, individuals with a disability place themselves into executive positions by virtue of the fact that only they know how all the parts of the network fit into their conception of the good life. Acting much like directors of large corporations, individuals seeking self-determination can exercise considerable control over how much and with which people and institutions to deal. It is a powerful position.

Continued . . .

It should be understood that this power does not come from manipulating others so that they become slaves to one's will, nor even from arranging events according to one's choosing. That is the power of the tyrant, the would-be master of circumstances who is soon conquered when circumstances become great enough.

Rather, the power that forever frees the individual from the force of circumstances and happenings decreed by fate is the power of the self-will unfolding its destiny. It is the power of the soul that realizes its strength is not dependent on physical autonomy or fortuitous circumstances or simply the absence of physical and social restraints. It is the power of the individual mind realizing itself; it is the power of the human spirit managing the material world.

In the essay "Fate," Ralph Waldo Emerson, speaking of the power that limits Fate, declares, "Forever wells up the impulse of choosing and acting in the soul. Intellect annuls Fate. So far as a man thinks, he is free."

Emerson finds self-reliance essential to any sense of independence. Nurturing self-reliance is particularly important for individuals with a disability because it enables those dependent by circumstance to fashion a lifestyle independent by spirit.

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Aequitron Medical, Inc. Kim White 14800 28th Ave., N. Minneapolis, MN 55441 1-800/824-7203 (LP6, LP5, LP4, LP3)

Bear Medical, Inc. Lawrence Ten Eyck 2085 Rustin Ave. Riverside, CA 92507 1-800/331-2327 (Bear 33)

J.H. Emerson Co. Jack Emerson 22 Cottage Park Ave. Cambridge, MA 02140 617/864-1414 (Poncho, cuirass, iron lung, etc.)

LIFECARE
Geoff Waters
655 Aspen Ridge Dr.
Lafayette, CO 80026
303/666-9234
(PLV100, PLV102, iron lung, rocking bed, etc.)

Puritan Bennett Corp.
Terry Preston
4865 Sterling Dr.
Boulder, CO 80301
1-800/248-0890
(Maxivent, Bantam, C2800, etc.)

W.S. (Sonny) Weingarten 401 E. 80th Ave. Denver, CO 80229 303/288-7575 (Porta-lung)

PROCEEDINGS OF THE HOME MECHANICAL VENTILATION WORKSHOP, G.I.N.I.'S FIFTH INTERNATIONAL POLIO & INDEPENDENT LIVING CONFERENCE, ST. LOUIS, JUNE 1989

ANESTHESIA IN SEVERE DISABILITY by Geoffrey Spencer, F.F.A.R.C.S.

Surgery and anesthesia are often a cause of fear and dread among disabled people, and almost as much among their medical advisors. This is a pity because people with disabilities are at least equally prone to all the surgical conditions affecting everyone else; sometimes more so because they are more likely to be injured in falls and motor car accidents and they may need surgery directly related to the disability, such as spinal surgery for scoliosis. A surgical condition that would be a minor problem to an otherwise ablebodied person can be a major problem to a person with a disability.

I am an anesthetist and I am in the unusual position of having my own beds, primarily for the respiratory care of people with disabilities. Some of the advantages of being an anesthetist are that I can give the anesthetic myself, choose the surgeon, and even exert some degree of influence over what the surgeon does as the operation proceeds. Also, because they are my own patients, I know them and how they live better than most anesthetists, and certainly more than the surgeon who is performing the operation.

Over the past 15 years we have performed surgery on 473 persons with severe disability. Of these, we conducted a study during the years 1982–1987 to compare the mortality with that in a control group of people with similar disabilities who did not need surgery. We also confined the study to those who had a respiratory disability which necessitated the use of a ventilator at home. This left us with 83 patients, ages 22–76 years old, who are the subjects of the study (submitted for publication in *The British Medical Journal*). These patients had one or more surgical procedures carried out under general anesthetic, all of which were given by me, for a consecutive series of 142 operations.

To classify ventilator use, we developed the St. Thomas' classification of respiratory independence as follows:

- Grade I includes those individuals who can breathe spontaneously normally but who need mechanical ventilation during minor illnesses.
- Grade II includes individuals who can breathe for themselves while they are awake but have a fairly low vital capacity and need some help with breathing during the night.
- Grade III includes those with an even lower vital capacity who can breathe on their own but need mechanical ventilation during the night and also during part of the day.
- Grade IV includes those who must use some form of mechanical ventilation all the time and who may have a tracheostomy.

A large number of the operations were orthopedic operations, such as spinal surgery, joint replace—ments, and tendon transplants. The largest single type of operation was urological, mostly urolithiasis or prostatectomy. Gynecologic operations included hysterectomies, laparoscopic sterilizations, and elective cesarean sections. The other operations ranged from carpal tunnel decompression to open heart surgery.

We are fortunate to have an iron lung, unforunately only available in the United Kingdom. that enables our successful perioperative management. The iron lung rotates so that the tank section has a sloping head with more room for the patient's chin, particularly important for someone with scoliosis whose shoulders are very often on a level with the ears. It also opens like an alligator's mouth, hinged in the head end. The whole tank chamber is suspended rather like a chicken spit so that it can be turned upside down. A section of the back can be removed in order to get to the patient, both for auscultation and for physiotherapy. A dial shows the cycling of the ventilator which the physiotherapist can see in order to do assisted coughing.

For the anesthesia itself, we use atropine premedication, thiopental induction, and handassisted ventilation, usually via a face mask, and maintenance with nitrous oxide and low concentrations of volatile agents, usually halothane. We replace blood loss for all losses greater than 200 ml, and this is necessary because people with disabilities have a greatly reduced blood volume and need transfusion much more quickly.

At the conclusion of surgery, our goal is to return people to their previous level and method of respiratory support as soon as possible. I was surprised at how quickly mouth piece positive pressure or nose piece positive pressure users can return to that system within a short while of an operation.

Grade IV patients with a tracheostomy can use their home ventilators without the need to change to a cuffed tracheostomy. Those with Grade II and III classifications are placed in the rotating iron lung until fully awake and then as necessary for physiotherapy and secretion clearance.

When an endotracheal tube has been used during major surgery, it is left in place and the patient ventilated through it until they are cardiovas—cularly stable or until the chest drains are removed, usually in a matter of hours and never longer than seven days. They are then placed in the rotating iron lung and the endotracheal tube removed in the lung. There is no doubt that the lung enables early extubation and makes the transfer from endotracheal tube to the patient's own ventilation system much easier.

We have had ten radiological and bacteriological postoperative complications, equally spread among the different classifications. All were successfully treated in the iron lung and none needed reintubation or other interference.

Three deaths occurred within 30 days of surgery which is the time limit set for the official report on inquiries into perioperative deaths. One death occurred in a 72-year-old with a C-2 spinal cord transection who underwent laparotomy for division of adhesions. He developed generalized peritonitis which was not actively treated in view of his general condition; he died on the seventh postoperative day. The second death was a 56-year-old polio survivor who suffered an internal capsule cerebral hemorrhage and died on the eighth day after emergency retrolithotomy. The third was a 28-year-old polio survivor drug abuser who underwent surgery for the incision of an injection site abscess and died 14 days postoperatively from a self-administered drug

overdose after he left hospital and went home. None of the deaths were thought to be directly attributable to surgery or anesthesia.

However, 18 of the study group died from six weeks to two years after surgery, usually from progressive disease, such as ALS, muscular dystrophy, carcinomatosis. The overall mortality in the surgical group was 20.4%, compared with 18.3% in the control group.

We concluded that the use of simple anesthetic techniques, minimal doses of muscle relaxants and narcotics combined with vigorous post-operative physiotherapy in the rotating iron lung, and early mobilization all permitted normal and even aggressive surgery to be performed.

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MUTUAL DECISION-MAKING: MUSCULAR DYSTROPHY by Agatha Colbert, M.D.

Increasing numbers of individuals with late stage Duchenne muscular dystrophy (DMD) are using mechanical ventilators to extend their lives. With this prolongation of life, we are seeing many previously unidentified complications as the muscle disease itself continues to progress. The decision to use assisted ventilation is a complex one for the individuals, their families, and physicians. To my knowledge, there are no protocols existing that address this dilemma. All parties involved have lacked information about the outcome **before** having to make a decision.

Physicians in general, although aware of the muscular and cardiac complications have not seen enough patients with advanced DMD to know about the swallowing problems, the gastrointestinal complications, the discomfort associated with a severe scoliosis and increasingly weakened musculature, and the further loss of pulmonary function. They are unable to tell their patients what to expect in terms of general health.

We are gaining more psychosocial data on the quality of life for individuals living with a ventilator, thanks to the efforts of Jessica Robins

Continued on p. 11 . . .

I.V.U.N. DIRECTORY 1989

This directory is a first attempt to compile the names of longtime ventilator users and health professionals who are experts about and advocates for home mechanical ventilation. As with any such attempt, omissions are inevitable. Please send additions and corrections to Judith Raymond Fischer, c/o I.V.U.N., 4502 Maryland Ave., St. Louis, MO 63108. Thank you.

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Miller and others. From these studies, it has become apparent that although opportunities for educational, vocational, and recreational endeavors have become more limited in this group of people, they still rank their overall quality of life as satisfactory. Their families, however, and for the most part this represents the perspectives of mothers, have acknowledged a significant change and a sense of being overwhelmed and very much restricted in their own lives because of the care demands resulting from an extension of their sons' lives.

As more data about the outcome becomes available we will be better able to provide information to those involved in the decision-making process. From a medical standpoint, we can anticipate when respiratory failure will develop and we now know that the use of a ventilator circumvents respiratory failure but does not halt progression of the disease. We also know that although initially an individual may require night-time ventilation only, his time using assisted ventilation will increase year by year.

We can tell the individuals themselves what life has been like for others who have opted for mechanical ventilation and at the same time give them permission to say no if that is their choice.

For families, we can change expectations early on, either at the time of diagnosis or when the child begins to use a wheelchair at about age 10 years, by saying that he does not necessarily have to die before age 20. Planning for the future will change considerably with the thought that their son may indeed have the time he wants to further his academic and/or vocational pursuits and that marriage and a family are also possibilities.

I see the role of the health care team as follows:

- helping individuals and families define what is important to their own quality of life -
- informing them whether those factors will be affected by the use of a ventilator and/or progression of the disease -
- advocating for more extended services in the community for educational, vocational, and recreational pursuits and opportunities for socialization and respite for families.

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GENERATIONS OF VENTILATORS: AN HISTORICAL PERSPECTIVE by Joseph Kaufert, Ph.D.

As a social scientist, I have a theory that we must understand respiratory technology from both the consumer side and the provider side – to look at the impact of changing technology on the life of the consumer and on the life of the professional involved in respiratory support. Many ventilator users have experienced three or four generations of technology.

I interviewed about 10 people who have used ventilators for at least 30-35 years since their initial experience in the iron lung. I talked with them about the way they viewed the technology, from an iron lung to a rocking bed to some form of combined assisted ventilation. They remember ed the acute stage in terms of survival and temporary necessity, but that stage influenced people's life experience so they see the new technology as filtered through that acute stage.

The rehabilitation stage saw a movement toward independent functioning and some weaning from the technology. The dilemma is that some of the psychological baggage from this stage -the tremendous emphasis on independence and avoidance of technology - now hinders a selective discarding of some of that emphasis on independence and a selective adopting of some of the technology.

The stability phase of the experience was very much associated with independent living. The professional respiratory technologist views this phase as one of invisibility. The consumer took the iron lung or the rocking bed or early positive pressure equipment home and disappeared into the community. Some professionals have forgotten that the consumers went out and did their own thing. They adapted the technology, they advocated for respiratory home care programs, and they spent 20–30 years with very little contact with either respiratory professionals or rehabilitation medicine.

In the early 1980s, people began to experience the breathing difficulties associated with the late effects of polio. They had gone through a 20-30 year period of being independent, of being consumers rather than patients. When they came back to talk with respiratory technologists and clinicians, they came with a unique body of exper-

tise about home care and ventilators and a very different attitude from what most clinicians and respiratory technologists were accustomed.

For example, the clinicians were very much into an ICU model of a tracheostomy, the emphasis on clinical efficacy and minimizing risk, but the consumers remembered the initial tracheostomy during the acute stage as old technology, as invasive and to be avoided at all costs. They had faced the risk of mortality issues for 20–30 years and were not so concerned that ICU standards be maintained. They liked familiar, userfriendly technology.

The new generation of positive pressure ventilators created in the States has created the need for local adaptations. As we move into more and more sophisticated forms of ventilators, the capability of the user and the respiratory technologist to modify the equipment has become more complex.

We need to document the diversity of first generation ventilator technology still being used within the community. (The rocking bed is sometimes viewed as an historical artifact although many people still use them in their own homes. It is often portrayed as the first generation of ventilator technology, but it belongs in the second generation.) We need to understand people who came out of an acute polio respiratory experience from both the consumer and the provider perspective. We need to reevaluate the regional respiratory centers that were so successful during the 1950s epidemics. We need to train the new respiratory technologists who are becoming more specialized to view their work from a consumer perspective. The clinicians and consumers must continue to confer as mutual experts who have developed an exciting approach that is "non-rehab."

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SWALLOWING MANAGEMENT AND TRACHEOSTOMY TUBES by Carl Coelho, Ph.D.

Swallowing is a complex act and it is even more complex for a ventilator user with a tracheostomy (trach) tube. The trach tube can restrict the upward laryngeal movement necessary for airway protection by anchoring the trachea to the strap muscles in the skin and neck. The tube also prevents the expired air from being shunted upward through the larynx. Most of the air will go out via the trach tube, so if a little bit of liquid or food has penetrated the larynx, it will be difficult to cough it out.

The laryngeal closure reflex is weakened anytime the upper airway is bypassed by the trach. The combination of the tethering effect of the tube on the larynx as well as a reduced protective laryngeal closure reflex can leave an individual with a trach with a diminished ability to cough and to protect the upper airway, leading to potential aspiration.

When the trach tube is cuffed, further complications occur. A cuffed trach is inflated to keep food, liquids, secretions, etc., from entering the lungs. If the cuff is not carefully inflated or is overinflated, there is a risk of esophageal restriction by the tracheoesophageal wall being pushed over into the esophagus and impeding the flow of the bolus into the esophagus, leading again to potential aspiration.

In my opinion, and I may have some disagreement on this, it is best not to have the cuff inflated when feeding takes place. The presence of an inflated cuff further prevents the air from clearing the larynx, and if the individual is aspirating foods or liquids, it is vital to know when it occurs, whether prior to the swallowing reflex, during the swallowing reflex, or after. The inflated cuff delays that knowledge. If the individual chooses to inflate the cuff during feeding, it is important that the individual be suctioned prior to the feeding, have the cuff deflated, and then suctioned immediately afterward.

The ideal position for swallowing is an upright one or as close to a 90 degree angle as possible. Head positioning can help with a minor modification of dropping the chin to widen the valle-

cular space. If the individual has any premature leakage of liquid or food from the oral cavity prior to swallowing, it will be caught in this space. In many individuals with a delayed swallowing reflex, the reflex is triggered in the area of the vallecular space or even in the piriform sinuses, so it buys a little more time.

Irritation can also develop if the overinflated cuff remains inflated for prolonged periods. A tracheoesophageal fistula or a hole can develop, causing aspiration for a totally different reason.

One advantage to having a trach tube is that if an individual is aspirating, he or she can see it immediately and remove the material that has been aspirated directly through the trach by suctioning.

A video fluoroscopic study can document the presence and degree of aspiration that a ventilator user may be having with swallowing. It can also facilitate management by identifying the best consistency of foods and liquids and the best position for feeding.

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NON-INVASIVE VENTILATION by Susan Sortor, R.R.T.

The rocking bed is considered out-dated by some medical personnel who are quick to change patients from this type of ventilation when they have an acute problem and must be hospitalized. One of our patients had atelectasis and a low vital capacity on the rocking bed, but did not want to change ventilation systems. We began an aggressive program of intermittent hyperinflation with postural drainage, percussion, and assisted coughing. After several days, blood gases and vital capacity improved enough for the patient to go home with daily IPPB treatments.

We use our iron lungs postoperatively, as Dr. Spencer does. We are able to quickly extubate and return people to their usual method of ventilation. We use the iron lung for individuals who get into some form of crisis, such as pneumonia or chest colds, and need assistance for a short period of time.

The Porta-lung is a fiberglass lung that we use with our pediatric patients. It is much smaller, lighter, and more portable than the iron lung. It can be lifted by two people and put in the back of a station wagon. Children with Werdnig-Hoffmann disease use it and find it very comfortable and suitable for night-time ventilation.

The Pulmo-wrap is used often with our spinal cord injured individuals, but there is a problem with skin breakdown because the person cannot feel the system coming into constant contact with the skin. The pneumosuit, a modification of the Pulmo-wrap, is made of Gore-tex for more durability and easier care. The infant pneumo-suit or pneumolung is really just a cage with the material around the cage. We used the pneumo-suit on a five-month-old infant with a C-5 spinal cord injury and with some diaphragmatic function to help extubate the infant.

Chest shells or cuirasses are good for day-time ventilation, but they require some degree of expertise in fitting the shell. Shells that are on the market rarely fit someone with scoliosis. Custom-fitted shells are best, and Dr. Spencer wrote an article in the *Gazette* (Vol 24, 1981, p. 49-50) describing how to make one.

The pneumobelt or exsufflation belt can be worn under clothing and is more aesthetically pleasing. It can be used only in an sitting position because it forces exhalation with inspiration passively occurring with the dropping of the diaphragm by gravity. It is preferred by our male spinal cord injured for day-time ventilation.

Positive pressure ventilation through the nose or mouth has spurred many creative adaptations. Masks can be held in place with or without straps or by the teeth. The videotape of the mask workshop illustrates the many varieties.

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CHANGING VENTILATORY NEEDS OF POLIO SURVIVORS by Redento Ferranti, M.D.

We have learned some of the answers to why a polio survivor who was weaned from a ventilator 20 years ago may need a ventilator again or why an individual may need to use a ventilator during the night or a few hours during the day. In people with respiratory muscle fatigue, progressive respiratory insuffiency, and hypoventilation, we can assess the arterial blood gases and measure carbon dioxide tension.

The technological process and the ability to obtain blood gas values has allowed us to improve the use of ventilatory assistance. The importance of other factors, such as nutrition, emphasizes the multifactorial component in ventilation and the need for ventilatory assistance.

Before we had arterial blood gases and intensive coronary care units, hypoxemia was probably not detected and treated in time. It was not uncommon for us to receive a patient for rehabilitation from an acute hospital who had been and still was severely hypoxemic.

Oxygen consumption is normally about 3% of the total need of the body, but during episodes of cardiorespiratory failure it can increase to 25%. During an illness when the heart is failing, the need for oxygen increases and the respiratory muscles must work harder. In cardiogenic shock, the diaphragm stops working, not because of the decreased neural input as once was thought, but because it is exhausted. We can demonstrate the neural input, but due to the increased need for oxygen nutrients, the diaphragm is failing to work.

Michael Fillyaw, M.S., P.T., of the University of Vermont, reminded us earlier that there are studies demonstrating why chronic fatigue due to productive work may lead to irreversible cellular damage. Short resistive exercise may indeed improve muscle strength when alternated with rest. Others have demonstrated that respir atory muscles can be trained for force and endurance. Resistive training in conditions such as stroke, paraplegia, etc., can be beneficial when done for a short time.

We have been working with Dr. Thomas Aldrich of Montefiore Hospital in New York to assess a protocol to enable us to wean patients from ventilators who could not be weaned for months in an acute hospital. This protocol requires that patients be cardiovascularly, nutritionally, and metabolically stabilized. We would start the weaning process in a different way: by short periods of assisted breathing until the muscle again would gain strength. A preliminary report has been published in the Journal of Clinical Medicine.

The selective use of technology will satisfy more and more the changing needs of polio survivors, but treatment must be individualized.

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More transcripts of the conference sessions on home mechanical ventilation will appear in the Spring 1990 issue of I.V.U.N. News.

/. V. U.N. News renewal notices will soon be sent to those readers who have not yet renewed for 1989. I.V.U.N. members will also have an opportunity to subscribe to <u>all</u> of the G.I.N.I. publications at a special rate.

Deadline for articles, stories, information, etc., for the Spring 1990 issue of *I.V.U.N. News* is January 15, 1990. Please submit to Judith Raymond Fischer, c.o./I.V.U.N., 4502 Maryland Ave., St. Louis, MO 63108.

BLITZER REPORT NO. 5: NOSE NEWS by Bud Blitzer

Alternative breathing aid equipment, including the latest fashions in nose and face masks, were a lively topic at the home mechanical ventilation work shop during G.I.N.I.'s Fifth International Polio & Independent Living Conference in St. Louis in June

An invaluable videotape of the mask session, with ventilator users showing off their own adaptations, is available for \$17.50 postpaid from Tim North, St. Louis Audio-Visual, 2114 Schuetz Rd., St. Louis MO 63146 (314/993-3388). Specify that you want Tape #14.

Another good videotape (#9, same price and source as above) reviews the different kinds of negative and positive pressure home ventilators.

Since the conference, I have heard from several people who left the workshop encouraged by what they saw, but disappointed because they did not know how to try out the devices they saw or how to purchase them. In an effort to alleviate that, I am now trying to track down all these ideas and put together a directory of mask sources around the world that will be published in *I. V.U.N. News.*

Address: Bud Blitzer, 400 S. Saltair, Los Angeles, CA 90049.

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Home mechanical ventilation workshop audio and videotapes from G.I.N.I.'s Fifth International Polio & Independent Living Conference are available from Tim North, St. Louis Audio-Visual, 2114 Schuetz Rd., St. Louis, MO 63146 (314/993-3388). The audiotapes are \$7 each, the video-tapes \$15 each, plus \$2.50 shipping:

Tape #10 - Muscular Dystrophy

Tape #11 - Home Ventilator Maintenance

Tape #12 - Travel with Ventilators

Tape *13 - Home Ventilation in Children & Adolescents.

Cofflators! Wanted by: Agatha Colbert, M.D., Lakeville Hospital, Lakeville, MA 02347, 508/947-1231 and Steven Linder, M.D., VA Medical Center, 3801 Miranda Ave., Palo Alto, CA 94304, 415/493-5000.

Wanted: LP3 parts needed by ventilator user. Contact I.V.U.N. offices, 4502 Maryland Ave., St. Louis, MO 63108.

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