

# POLIO NETWORK NEWS

FALL 1995 ♦ ♦ ♦ ♦ VOL. 11, NO. 4



Sixth International Post-Polio and Independent Living Conference, Fall 1994

## FACING SURGERY WHEN BREATHING IS A PROBLEM

### Scoliosis, Ventilation, & Surgery

Augusta Alba, MD, DNP-N, DPM&R, Goldwater Memorial Hospital, New York, New York

How does scoliosis affect breathing? Consider a typical, moderate curve of the spine of an individual. We usually look at the outside of the body to determine what is happening to the inside of the body, to the lungs, and the heart. The twisting of the ribs backwards causes the lung to be similarly twisted into that shape and partially compressed. Distortion of the lung happens not only on the side of the convexity, but on the other side as well, the side of concavity.

When considering breathing, we are particularly interested in the cervicothoracic curve (apex at C7-T1), the thoracic curve (apex between T2-T11), and the thoracolumbar curve (apex at T12-L1). These are the ones that can affect cardiopulmonary function. Curves are classified by the number of degrees of lateral curvature. Curves in group III (31-50°) and group IV (51-70°) and beyond are the ones that cause more problems insofar as anesthesia and surgery are concerned.

There are several specific neuromuscular diseases which can cause curvatures including muscular dystrophies, spinal muscular atrophy, cerebral palsy, spinal cord injury, spina bifida, and arthrogryposis. Post-polio scoliosis is probably most similar to the scoliosis associated with spinal muscular atrophy. For the person with neuromuscular scoliosis, it is important to know specific management techniques when the curve is the result of muscle weakness.

The surgical treatment of scoliosis has already been discussed (*Polio Network News*, Vol. 11, Nos. 2 & 3). Non-surgical treatments include observation, bracing, custom seating, and electrical stimulation which for the most part has fallen out of favor, because it has not proved to prevent further progression of the curve. Postural exercises, exercises to maintain spinal flexibil-

continued on page 3

## NEW BREATHING PROBLEMS IN AGING POLIO SURVIVORS

### Respiratory Muscle Weakness

Ann Romaker, MD, Kansas City, Missouri

In my pulmonary practice over the past 15 years, I have seen individuals who have a history of polio and who have respiratory problems but are unaware of them. Only one required ventilatory support during acute polio, and one other had known bulbar polio. The others had isolated or extensive limb involvement, even quadriplegia. Most had involvement in just a single limb. When studied, all of them had measurable respiratory muscle weakness. Anyone with a prior history of a neuromuscular disease, such as polio, needs to be evaluated in depth before and around stressful, physiologic events such as surgery.

**Function of the respiratory muscles ...** The diaphragm is the major muscle of breathing and its descent increases the length of the thorax and increases lung capacity. The external intercostal muscles pull the ribs up and out. The scalene muscles raise the rib cage and the sternum (or breastbone). Another muscle, the sternocleidomastoid, elevates and expands the rib cage. Negative pressure is created within the chest, and the increase in the dimension of the chest increases the volume of the lungs. Air then enters the lungs through the nose, and is inspired.

Expiration is a much less active process. The abdominal muscles pull the ribs down and push the diaphragm up. The internal intercostal muscles pull the ribs down and in and squeeze the air out. If either the inspiratory or expiratory muscle groups, or both, are not functioning properly, some type of respiratory assistance may be needed.

**Representative case ...** An individual with involvement (that she was aware of) only in her legs and who wears leg braces, works full time as a nurse. After routine gynecologic surgery, she developed pneumonia

continued on page 7

# Post-Polio Breathing and Sleep Problems

Judith R. Fischer and Joan L. Headley

New breathing and sleep problems in aging polio survivors can be insidious and often not recognized by either polio survivors themselves or health care professionals. Polio survivors who were in an iron lung or barely escaped one during the acute phase should be aware of potential problems and educate themselves in order to avoid acute respiratory failure. Polio survivors who did not need ventilatory assistance during the acute phase may also be at risk for respiratory failure, and should likewise be aware of problems with breathing and sleep.

Simply stated, the major problem for polio survivors is hypoventilation (commonly referred to as underventilation). Not enough air reaches the lungs, producing an imbalance in the gas exchange in the blood: too little oxygen, too much carbon dioxide (CO<sub>2</sub>) or hypercapnia. Hypoventilation is caused by one or a combination of the following: chest wall deformities such as scoliosis (see page 1 article by Augusta S. Alba, MD), respiratory muscle weakness due to the poliomyelitis (see page 1 article by Ann Romaker, MD), and sleep apnea (an interruption of breathing during sleep) which can be central, obstructive, or mixed, and occurs in the general population as well.

Other factors contributing to a polio survivor's problems are a history of smoking, obesity, lung disease, and diminished vital capacity (VC). As aging occurs in anyone, vital capacity (VC) diminishes, but this decrease in VC is more serious in an aging polio survivor with limited musculature remaining to produce adequate ventilation. Many polio survivors had impairment of the diaphragmatic and intercostal muscles, and the normal changes due to aging may cause them to lose VC at a greater rate, thus exacerbating the development of hypoventilation.

Signs and symptoms include: fatigue, daytime sleepiness, morning headaches, need to sleep sitting up, sleep disturbances (including dreams of being smothered, nightmares, restless sleep, interrupted sleep), snoring, poor concentration and impaired intellectual function, shortness of breath on exertion, claustrophobia and/or feeling that the air in the room is somehow bad, anxiety, difficulty in speaking for more than a short time, quiet speech with fewer words per breath, use of accessory muscles to breathe, and a weak cough with increased susceptibility to respiratory infections and pneumonias.

Polio survivors experiencing more than one of the above signs and symptoms should seek a respiratory evaluation by a pulmonologist, preferably one experienced in chronic neuromuscular disorders. (If your pulmonologist is unfamiliar with post-polio, you may wish to provide copies of pertinent literature listed under References, or offer to connect him or her with a physician in the I.V.U.N. Network.) Pulmonary function tests should include at least: VC, air flow, MIF (maximum inspiratory force) and MEF (maximum expiratory force), and ABG (arterial blood gases). A sleep study should also be considered, however, strong anecdotal evidence from polio survivors indicates that a

sleep study may miss detection of hypoventilation. A sleep study is designed to detect sleep disturbances, such as sleep apnea; it does not measure CO<sub>2</sub>.

Management of breathing and sleep problems can be achieved largely through the use of nocturnal noninvasive ventilation, in the form of mouth intermittent positive pressure ventilation, nasal intermittent positive pressure ventilation (a variety of commercial and custom nasal/face masks are available — see References), and negative pressure body ventilators. However, polio survivors may find themselves gradually extending periods of ventilator use. In some cases, as a last resort, invasive tracheostomy positive pressure may be necessary.

Medical literature regarding the management of breathing problems often includes a warning about the use of oxygen therapy. Respiratory failure in polio survivors is usually due to hypoventilation which can be aggravated by the short and long term use of oxygen. When the brain senses an excess concentration of CO<sub>2</sub> in the blood it instructs the body to increase breathing, ridding it of the CO<sub>2</sub> and increasing the oxygen. When oxygen is supplied, the mechanism in the brain detecting the CO<sub>2</sub> eventually turns off. Hypercapnia is best treated with assisted ventilation.

Polio survivors with different problems, such as COPD or pneumonia, may benefit from short term oxygen therapy under careful supervision. □

Thanks to Edward A. Oppenheimer, MD and John R. Bach, MD, for reviewing this article.

## REFERENCES:

\*Advice for People with Polio or Other Neuromuscular Disorders by Augusta Alba, MD, and Alice Nolan, RN; *Rehabilitation Gazette*, Vol. 23, 1980.

Evaluation and Management of Post-Polio Respiratory Sequelae: Non-Invasive Options by John R. Bach, MD; Chapter 6, *Post-Polio Syndrome* (ISBN 1-56053-117-7) edited by Halstead and Grimby, published by Hanley and Belfus, Inc., Philadelphia, PA (800/962-1982).

Suggestions for Avoiding Respiratory Complications by John R. Bach, MD; *I.V.U.N. News*, Vol. 9, No. 2, Fall 1995.

Severe Hypercapnia After Low-Flow Oxygen in Patients With Neuro-muscular Disease and Diaphragmatic Dysfunction by Peter C. Gay, MD and Lee C. Edmonds, MD; *Mayo Clinic Proceedings*, Vol. 70, pp. 327-330; Editorial pp. 403-404, April 1995.

Noninvasive Ventilation: Does It Work, for Whom and How? By Nicholas S. Hill, MD; *American Review of Respiratory Disease*, Vol. 147, pp. 1050-1055, 1993.

Comparison of Commercial and Custom Nasal/Face Masks by Susan Sortor Leger, RRT; *I.V.U.N. News*, Vol. 9, No. 1, Spring 1995.

The Diagnosis of Underventilation Following Polio and Treatment of Underventilation by Day and by Night by G.T. Spencer, FAARCS; *I.V.U.N. News*, Vol. 2, No. 2, Fall 1988.

\*Available by sending a self-addressed #10 envelope with 32¢ postage to G.I.N.I., 4207 Lindell Blvd., #110, St. Louis, MO 63108-2915 USA.

\*\* *I.V.U.N. News*, a bi-annual newsletter edited by Judith R. Fischer, links ventilator users and health care professionals. The annual subscription fee is \$12 USA; \$15 Canada/Mexico, surface; \$17 airmail. A complete set of 18 back issues is available for \$25 postpaid. To order, contact G.I.N.I., 4207 Lindell Blvd., #110, St. Louis, MO 63108-2915 USA.

## **Facing Surgery When Breathing Is a Problem:**

### **Scoliosis, Ventilation, & Surgery**

continued from page 1

ity, and other exercise routines are helpful and must be individualized. Physical therapists specializing in the treatment of scoliosis can provide this training.

For polio survivors with scoliosis, the main problem is a reduction of the biggest breath one can take. When the ability to breathe in deeply is impaired, the tidal volume (volume inspired with each breath) becomes smaller. Respiratory rate then becomes more rapid in order to maintain adequate ventilation. When a person is breathing more rapidly, the amount of air that actually reaches into the distal parts of the lungs where gas exchange occurs, the alveoli, is less. The work of breathing is increased because the flexibility of the chest wall is decreased due to the scoliosis. If the work is increased, the oxygen cost of breathing is also increased.

**What is the result of inadequate ventilation due to a scoliotic chest wall?** One develops an increased resistance in the circulatory system of the lung which leads to hypertension of the pulmonary artery system — the system which sends blood to the lungs from the heart. If pressure in the pulmonary artery increases, the right side of the heart becomes enlarged and hypertrophied. The heart muscle becomes thicker in an effort to pump blood against a higher pressure. If the scoliosis is not corrected, the heart eventually dilates. This condition is known as cor pulmonale.

With a scoliotic curve there can be a displacement of the heart within the chest, with it sometimes appearing to be on the right side of the chest. The aorta, which is the major blood vessel of the body, may also be twisted to follow the scoliotic curve. It is rarely kinked. The ultimate outcome with inadequate ventilation is congestive heart failure.

**What recommendations can be made when polio survivors with breathing problems are facing surgery?** There is no special pre-op or post-op care if the vital capacity is 70 to 100% of normal, with a good ability to cough, and if expiratory peak flow, hemoglobin, and EKG are normal.

If curvature and neuromuscular weakness have decreased the vital capacity to 50 to 70% of normal, the expiratory flow is slightly reduced, and hemoglobin is slightly elevated but EKG is normal, pre-op management is regular. However, post-op management should include intermittent positive pressure breathing treatments on a regular basis with assisted coughing.

When vital capacity is further decreased to 30 to 50%, there are more serious problems affecting the heart and lungs. Expiratory flow is markedly reduced, and hemoglobin is elevated above normal. With the secondary complication of increased hemoglobin, the blood is more viscous which increases the chance of thrombo-

sis. The EKG reflects the increased size and hypertrophy of the right side of the heart. Pre-op management must include assisted ventilation on a regular basis and, if improvement occurs, then surgery can be considered.

If assisted ventilation helps pre-op, continue it post-op on an indefinite basis so that hemoglobin and carbon dioxide will not be elevated and oxygen will not be depressed.

In post-op management, artificial ventilation should continue until the individual has regained at least 75% of pre-op vital capacity (VC). Aerosol mists with assisted cough; frequent turning to prevent atelectasis (small mucus plugs in the lung); and a limit on post-op sedation, which reduces the ability to breathe deeply and to cough, are recommended.

Persons with scoliosis with 10 to 30% of predicted VC may have a greater degree of cor pulmonale, a further increase of hemoglobin and will need even more assisted ventilation. If the persons is helped by assisted ventilation, then proceed with surgery. In some cases with vital capacity in the 10 to 30% range and the 30 to 50% range, consider a pre-op tracheostomy.

The post-op treatment of people with 10 to 30% of predicted VC is the same as that for persons with 30 to 50%.

## **Considerations Before Surgery**

*Oscar A. Schwartz, MD, FCCP, St. Louis, Missouri*

Certain polio survivors may be at increased risk for surgical procedures, and the benefits must be weighed with the risks for determining candidacy. Prior to surgery, a good evaluation of the respiratory system is necessary. Polio survivors can develop breathing problems due to weakness of muscles originally (and obviously) involved with polio as well as those partially compromised but continuing to function. The effects of scoliosis also need to be considered, as Dr. Alba has discussed.

The evaluation should focus on the individual's reason for going into surgery as well as the complications that may result from anesthesia. Anesthetic complications can include those which are secondary to the general anesthetic, as well as those which may be complications of use of the anesthetic. The program that is developed should have the goals of supporting the respiratory system if it is impaired, or decreasing the amount of risk associated with the surgical procedure.

Patient-focused care involves a team. Team members are determined by the type of surgery whether it involves surgery of the spine or abdominal surgery such as gallbladder, colon surgery, or hysterectomy. The team is established so that the surgeon, anesthesiolo-

continued on page 4



## **Facing Surgery When Breathing Is a Problem: Considerations Before Surgery**

continued from page 3

gist, as well as the professional following the polio survivor, communicate with each other.

With healthy individuals, surgical procedures may have limited risk. In polio survivors, even minor surgical procedures that involve general anesthetics or nerve blocks that may paralyze the only functioning respiratory muscles may have disastrous effects.

Individuals who are diaphragm breathers may have response to inhaled anesthetic totally different from those who use the diaphragm as well as the intercostal muscles to breathe. Swallowing difficulties are of concern because of the potential risk of aspiration associated with the general anesthetic. Anesthesia can further compromise muscles in the head and neck area that may be involved with swallowing or breathing. Polio survivors should understand what the anesthesiologist will do and feel at ease with the procedure used.

After surgery, respiratory support may involve facilitation of cough. Support with a ventilator may be necessary, especially if the individual had a preexisting need for one. The post-operative period may be longer for polio survivors.

## **Preparing for Surgery**

*Kathleen Navarre, PhD, Essexville, Michigan*

When I was six years I had bulbar polio as well as paralysis in my upper and lower body. In 1991 through the network, I connected with Oscar A. Schwartz, MD, in St. Louis. Since that time I have used LIFECARE's PLV-100 ventilator with a Respironics face mask for night-time ventilation. I am back to driving and teaching full time. I feel quite alive, and delighted to be so.

My experience with surgery, in 1993, was not a polio issue; it was a hysterectomy. I came to St. Louis to have the support of Dr. Schwartz and the team at St. Mary's Health Center which paid off for I was back in the classroom five weeks after the surgery.

My greatest fear as a polio survivor with breathing problems was the thought of abandoning myself to an anesthetic and letting something take over my breathing for me. I am a sensitizer (a person with internal locus of control), so to face this traumatic experience, I gathered all the details, even the gory ones. I suspect that most of us attending this conference want all of the information we can get.

Others come under the label of repressors (individuals who have an external locus of control). They say in essence to a physician, "Do whatever you need to do and wake me up when it is over." That is fine, too.

Having an internal or external locus of control or being a repressor or sensitizer is neither good nor bad. Recognize which you are and make it very clear to your physician.

When my sister and I walked into St. Mary's Health Center for my surgery, there was an iron lung in the hallway. Being a sensitizer, I said, "Oh, my goodness Mare, that's for me." Being a repressor, she said, "Oh no, that's always there." I responded, "There's about four inches of dust on it. Obviously it's been in a closet since 1954." I was iron lung phobic but I wanted to touch it, to feel it. After I did touch it and put my hands in it, and sort of kicked a tire or two, I felt better about it. Because it was Halloween, the nurses discussed putting a pumpkin at the head and that humorous idea made me feel more comfortable. (The iron lung was there for me in case I required it after surgery, but it was not needed.)

They tried to do a spinal for my surgery which did not work because of my scoliosis. It was impossible to provide the necessary regional anesthesia. I did receive a general anesthesia with appropriate intubation. My recovery was normal in terms of time.

### **Kathleen offers these suggestions for adjusting to using a face mask:**

- ▲ Start with several 15-20 minute intervals on the mask during the day.
- ▲ Relax, watch TV, read, try to distract yourself to stay relaxed.
- ▲ Get into the rhythm of the vent's breathing by slowly letting it take over.
- ▲ During the first few nights, wake up, sit up, clear your head, and then start over again.
- ▲ At first the vent feels like a smothering enemy, but it will become a life-affirming friend. Give it a chance.

## **Arranging for Anesthesia**

*Judi Cox, Springfield, Illinois*

For polio survivors, particularly ventilator users, anesthesia is not a pleasant undertaking. On two occasions I have needed to prepare for surgery with general anesthesia. With a knowledgeable pulmonologist as part of the physician, surgeon, and anesthesiology team at Memorial Medical Center in Springfield, Illinois, things went well.

I am a 56-year-old female who had all three types of polio at age 14 (1952). The initial attack resulted in quadriplegia and being in the iron lung for the first nine months. In the two years that followed, I used a cuirass, then a rocking bed, slowly progressing to inde-

pendent breathing. After months at Warm Springs, Georgia, I learned to walk independently.

In 1992 while going to work at a large regional hospital, I collapsed from respiratory failure. There had been months of extreme fatigue requiring return to a wheelchair and retirement from work. Since then I have used night-time ventilation with Aequitron's LP-6. With pacing, I have enjoyed retirement.

Because of my history, anesthesia was considered a risk. I researched and prepared as much data as possible about my status and discussed it thoroughly with the surgeon and anesthesia team members. We discussed oxygen sensitivity, cold sensitivity, uncomfortable positioning, recent symptoms of concern, and a list of questions, e.g., how long will the procedure last, etc.

The team felt I might go to ICU still intubated and could possibly remain on the ventilator for 24 hours post-op. I shared my concerns and my hope to get my mask and vent back as soon as possible. Because of pre-planning, they removed the tube when I was fully awake in the recovery room and in eight hours post-op I was back with my own equipment. Using the LP-6 quite a bit over the next two days prevented any adverse effects of the anesthesia. Also, using minimal pain medication eliminated further problems. Nebulizer treatments and aid in coughing over the three to four days post-operatively helped with the mucus.

As part of the team, I prepared folders (typed and easy to read) for each person on the surgical team that included the following:

- ▲ A complete current medical history and brief detail regarding systems and possible complications, e.g., cardiovascular system: see attached echocardiogram 3/7/93, including extra data such as copies of relevant records of arterial blood gases, sleep tests, etc., for baseline comparison.
- ▲ A page describing allergies and how they are manifested, e.g., morphine causes a rash, and documenting other precautions such as no muscle relaxants and minimal pain medication.
- ▲ A page regarding the home mechanical ventilator and mask listing types, settings, sizes, facts, etc. (It may be necessary for the hospital to check with the legal department clearing the use of your own equipment.)
- ▲ A list of specific questions for each team member including ways I could assist myself and information about others involved in my care.
- ▲ Copies of pertinent literature, keeping it brief and highlighting data. (*Preparing for Surgical Interventions*, in "Pulmonary Dysfunction and Sleep Disordered Breathing as Post-Polio Sequelae: Evaluation and Management," written by John R. Bach, MD, and Augusta S. Alba, MD, published in *Orthopedics*, Dec. 1991, Vol. 14, No. 12 is excellent.)

Physicians will appreciate your efforts and provide the best care possible because of your thorough knowl-

edge. You will have peace of mind as a responsible contributor to your care as well as to the team. Trust them and, when possible, find humor together in the uniqueness of your situation.

## Dealing with Breast Cancer Surgery

*Ellen Fay Peak, Birmingham, Alabama*

When I was diagnosed with cancer in my right breast on March 2, 1995, my first thought was not "Am I going to die?" but "Am I going to be able to type and feed myself?" On April 3rd the surgeon, whom I ultimately chose, first examined me and said that it would have to come out. I responded, "No, it does not have to come out." He listened closely as I explained the history of my arm and shoulder limitations and watched carefully as I, naked from the waist up, demonstrated my very narrow range of arm and hand use, a range so narrow that I must have full-time physical assistance. There I was in a doctor's office trying to prove that my body had enough to do in dealing with the late effects of polio. Cancer did not scare me. It was the treatment of cancer that tore me up.

What was I doing between March 2nd and April 3rd? On the same day that I learned that I had breast cancer from a routine mammogram, I had a sonar exam of the mass in my right breast, consultations with two surgeons, and a needle-core biopsy. Although the surgeons concurred with the idea of immediate surgery followed by radiation, I decided to do nothing until I had more information. I obtained some of the most useful from a friend who had undergone a modified radical mastectomy. Upon hearing my diagnosis, she came immediately to show me the results of her surgery, pointing out where muscles had been removed from her chestwall and down her underarm. She examined my breast and shoulder, drawing her fingers down my skin where the path of a surgery like hers would be. From that discussion, we determined that a simple mastectomy was as much as I could have and still use my arm. Anytime I needed her to, she would come and strip down and let me ponder my decision. She served as both my model and my patient advocate, putting forth ideas and intervening as needed.

On March 13, to try to determine if the cancer had spread beyond my breast, I had a bone scan, additional x-rays of my hips, and a chest x-ray, all of which appeared to be normal. Having pretty much decided that I would have no surgery that required general anesthesia, I then investigated radiation therapy. Because of shoulder tightness, my arm could not be positioned for radiation.

I sought advice by phone and letter from doctors who knew me well. I discussed each development with my

continued on page 6

**Facing Surgery When Breathing Is a Problem:  
Dealing with Breast Cancer Surgery**

continued from page 5

long-time internist who encouraged me to explore every avenue of information before making any decision. I had several informative conversations with the Medical Director of Post-Polio Services at Roosevelt Warm Springs (Georgia) Institute for Rehabilitation. His having my early polio records and those from his own evaluations of me through the years proved invaluable as we talked about the possible effects of general anesthesia and the types of breast surgery.

I pulled out *Anaesthesia: Considerations for Polio Survivors*, an article I had saved from the Fall 1991 issue of *Polio Network News*, and copies of both Dr. Susan Love's *Breast Book* and *Post-Polio Syndrome* by Halstead and Grimby. Because I was in the middle of planning the program for a state-wide forum sponsored by the Birmingham Post-Polio Support Group, I took the opportunity to discuss my situation with three of the major speakers. Each responded to my questions, providing me with an unexpected source of polio expertise.

Finally, I was in my surgeon's office arguing the fine points of tissue removal so as to preserve the little use I had of my right shoulder and arm: which lymph nodes I was willing for him to remove and what type of mastectomy I was willing for him to perform. I left there with a tentative surgery date, April 18th, to remove both breasts (the left breast looked threatening) and appointments with three more specialists to consult:

the anesthesiologist, the pulmonary doctor, and the physical therapist.

***On April 12th, I wrote the following letter to my surgeon, sending a copy to everyone else involved:***

When I recently spoke with the Director of International Polio Network about my impending surgery and my agitation about my functioning afterwards, she pointed out that she knew of no situation like mine. Thus, I feel compelled to continue to provide my physicians with as much information as I can about my polio state. As an upside-down polio quadriplegic since 1936, with post-polio syndrome since the late '70s, I am functioning at the outer edge of possibility. Once my assistant, Kay, dresses me in the morning, I wash my face, brush my teeth, and feed myself, all with my right arm helping my left. For exercise throughout the day, Kay helps me to my feet and I walk around inside my house with either her help or a walker. The walker is merely a balancing tool. I cannot put any weight on it. I spend most of my day at my computer, my right arm supported in a sling attached to my office chair, typing with the eraser end of a pencil between my fingers (my left hand controls the mouse). Otherwise, I read and converse on the phone, activities that require the use of both my right and left arms.

I further say that, aside from its pain, cancer holds no more threat to me than polio. I am not in awe of it. I view it simply as one more possible obstacle to my functioning. Although in the past I have overcome many such obstacles, I now have so little margin of function left that I am doing everything within my power to protect it. First, I have chosen my surgeon carefully, indeed, with more care than I chose my internist, in those carefree days of the mid-'70s. Although that choice was kind of dumb luck, it has turned out to be one of my very best. I have discussed my situation with the individual I hope to have as my anesthesiologist. I have been evaluated by the physical therapist who will work with me after surgery. I have had the benefit of my internist's expertise, interest, and counsel at every step along the way.

As to the actual surgery: I understand that no paralyzing or other such compromising drugs will be used during the anesthesiological process. I also understand that you will remove both of my breasts and the first level only of the lymph nodes under my right arm. I would be very pleased if you decided to remove no lymph nodes!

Beyond the surgery: I plan to have no additional therapy beyond the drug Tamoxifen, or its like; plan to partake of inhalation therapy; and interact with the physical therapist to regain the function I now have, not expecting to be rehabilitated out of my wheelchair.

Finally, but perhaps most important, here are some facts to know about me that are a result of my particular bout with polio. Others have their own strangenesses.

**INTERNATIONAL POLIO NETWORK**

4207 Lindell Blvd., #110  
St. Louis, MO 63108-2915 U.S.A.  
314/534-0475  
314/534-5070 Fax

ISSN 1066-5331

*Polio Network News is an international newsletter for polio survivors, health professionals, and resource centers, to exchange information, encourage research, and promote networking among the post-polio community.*

ISSUED QUARTERLY

**EDITOR/EXECUTIVE DIRECTOR:** Joan L. Headley

**PUBLISHER:**

Gazette International Networking Institute (G.I.N.I.)  
4207 Lindell Blvd, #110, St. Louis, MO 63108-2915 U.S.A.  
314/534-0475

**SPECIAL THANKS TO:**

Judith R. Fischer, A.J. Nadeau, Roberta Simon

**ANNUAL SUBSCRIPTION:**

U.S.A ♦ \$16 (U.S. dollars only)  
CANADA, MEXICO & OVERSEAS (Surface) ♦ \$21  
(U.S. dollars or Canadian equivalent)  
OVERSEAS (Air) ♦ \$25 (U.S. dollars only)

Copyright ©1995 by Gazette International Networking Institute  
Permission to reprint portions must be obtained from the Editor.



Because of my lack of muscle mass, I am unable to generate body heat if I am chilled. Warm to you may be chilling to me. When I am chilled, I feel great fatigue; my veins contract. Things that have chilled me in the past are: air conditioning not adjusted for me; cold tables; refrigerated saline to humidify oxygen; refrigerated IV fluids; iced drinks, including water, etc.

The left side of my throat is weaker than the right; thus I am susceptible to choking on liquids.

Like the extremely elderly, I am very reactive to the effects of medicine; thus, I have always worked under the plan of starting with the lowest possible dose of any new medicine, and sometimes I wind up taking less than that.

These are my thoughts for the moment; now I can only hope for the success of all.

**After-surgery note:** I wish I had added to the list above two items. Because of my lack of muscle mass, my limbs offer no resistance to such things as blood-pressure cuffs, blood-work tourniquets, and manual positionings. My worst pain and a soreness that is still with me arose from the unnatural (to me) manipulation of my right shoulder on the operating table while I was under anesthesia.

Because of my enervated shoulder muscles, even the closure of incisions near my underarms became a major problem. The slightest roughness/lumpishness in that spot created a kind of a speed bump to my already-limited arm motion. I have recently had plastic surgery (under a local) to smooth out my right underarm.

I came through all of the surgery with little, if any, loss of function. Perhaps my arms and shoulders tire more quickly, but I am pleased that they serve me as well as they do. As for the cancer, the pathology report indicates that it was Stage One with negative lymph nodes, which means that it was caught early enough not to require follow-up radiation or chemotherapy. And because it contained no estrogen receptors, I am not even taking Tamoxifen. □

#### Related resources:

Anesthetic Implications of Poliomyelitis by Joseph D. Tobias, MD; *The American Journal of Anesthesiology*, March/April 1995, pp. 102-104.

New Neuromuscular Blocking Drugs by Jennifer M. Hunter, MB; *The New England Journal of Medicine*, Vol. 332, No. 25, pp. 1691-1699.

#### **New Breathing Problems in Aging Polio Survivors: Respiratory Muscles Weakness**

continued from page 1

and had problems maintaining an adequate oxygen level. I was called in because the gynecologist and internist did not understand why the chest x-ray would not clear and why her oxygen level was so low. The first thing I ordered was a pulmonary function test to determine how strong her respiratory muscles actually were.

**Pulmonary function tests ...** In my opinion, the most accurate is a specific test of muscle strength. Some call it maximum inspiratory pressure. We call it negative inspiratory force. Expiratory strength can be measured by blowing as hard as possible against a resistance. We measure how much force is generated when someone tries to take a breath against an occluded mouthpiece. How hard one struggles to take a breath reveals how strong the respiratory muscles are. These special tests are helpful, easy to do, and they can be done at the bed-side. However, not all hospitals are properly equipped.

Standard respiratory testing involves having a clip placed over the nose while blowing as hard as possible. This measures actual lung volume and the ability to push air out in one second. Results of standard respiratory testing can give an indication of respiratory muscle weakness.

If any of the breathing muscles are weak, lung capacity and ability to expel air are reduced proportionally. It is important to note that with repeated effort most people have a learning curve and will get better results over the first three or four tries. On the contrary, someone with muscle weakness, who is asked to work harder and harder, will get worse with each try. A knowledgeable pulmonologist looking at that pattern will recommend tests to measure respiratory muscle strength.

**Representative case ...** The individual referred to earlier did have a significant decrease in respiratory muscle strength. The normal amount of pressure generated to breathe against an occlusion is about minus 60 to 70 centimeters of water pressure. She was generating about minus 20. As a matter of fact, no individual with prior neuromuscular disease who has been tested in my practice has done better than minus 26.

**Stressors on the breathing system ...** There may be no consequences of respiratory muscle weakness at all for someone in the minus 30 to minus 40 category until the breathing system is stressed, and surgery is often the stressor that highlights the fact that one has weak breathing muscles.

Infections also can highlight weak breathing muscles. If some find it difficult to cough, which is another function of the respiratory muscles, and have severe pneumonia, they may have difficulty clearing secretions, trouble maintaining oxygenation, and problems recovering from respiratory infection. Individuals with difficulty coughing due to weak muscles also may have a tendency toward bronchitis.

Medications also may unmask respiratory muscle weakness. Some post-polio individuals who believe they do not have respiratory weakness may take sleeping pills and then cannot cough, or take a deep breath. Others can react the same way to pain medications.

continued on page 8

## **New Breathing Problems in Aging Polio Survivors: Respiratory Muscles Weakness**

continued from page 7

The respiratory weakness appears with the use of the medication.

Exercise can also be the trigger. Polio survivors who do not recognize their respiratory muscle weakness may live a fairly sedentary life noting that they are short of breath with exercise and then quit exercising. When they are forced into vigorous exercise, their respiratory weakness becomes apparent.

Others who are not aware of any particular breathing problem show problems during sleep when studied. Everyone's tidal volume drops when sleeping, as does the oxygen level. People with respiratory muscle weakness may present initially with problems just during sleep which is why sleep studies are recommended.

If one has weak respiratory muscles and is overweight, the muscles are required to do more work. People with borderline respiratory muscle function may do just fine at a normal weight but may not be able to tolerate an extra 30 pounds. People who are borderline live fairly normal lives. However, they do not handle physiologic stress too well and may develop chronic respiratory insufficiency resulting in exercise limitation, abnormal gas exchange (with low oxygen and a rise in carbon dioxide), and profound oxygen desaturation during sleep which can cause strain on the right side of the heart and possibly cor pulmonale. One can develop acute respiratory failure from respiratory muscle weakness in conjunction with a physiologic stressful event. This situation requires mechanical ventilation immediately.

Other conditions of concern are the ability of the esophagus to function, dysphagia (swallowing problems), and aspiration (taking in of fluid or particles of food in the lung).

**Suggestions for management ...** Support for people who have weak respiratory muscles includes aggressively treating infections and regularly implementing chest physical therapy which can be done at home when someone has bronchitis. However, when someone has an infection and trouble coughing, more assistance may be needed. Many hospitals do not have the older IPPB (intermittent positive pressure breathing) machine, but the same principle can be employed with intermittent CPAP (continuous positive airway pressure). It is generally prescribed 15 minutes four times a day resulting in considerable improvement in the movement of air in the lungs decreasing atelectasis (small mucus plugs in the lungs).

Another support for respiratory muscle weakness is rest. The breathing muscles can be rested at night by using one of the many types of ventilation assistance. □

## **Terms Used in Vignettes**

**CPAP** stands for continuous positive airway pressure. Air flows continuously through a hose to a mask over the nose to keep the airway open during sleep. CPAP is used in treating obstructive sleep apnea. Several companies manufacture CPAP machines.

**BiPAP® System** provides two different pressure levels of air, one for inhalation and a lesser pressure on exhalation. It can provide a timed respiratory rate; can "spontaneously" sense the user's effort to breathe and the pressure changes accordingly to offer a pressure support breath; and can be set at a minimum breathing rate known as a backup rate. It is manufactured by Respironics, Inc., 1001 Murryridge Dr., Murrysville, PA 15668-8550 (800/345-6443).

BiPAP® System is known in the industry as a bi-level pressure device. Other manufacturers make bi-level pressure devices. Companion 320 I/E Bilevel is manufactured by Puritan-Bennett, 4865 Sterling Dr., Boulder, CO 80301 (800/248-0890). Quantam PSV (pressure support ventilator) is manufactured by Healthdyne Technologies, 1255 Kennestone Circle, Marietta, GA 30066 (770/499-1212). It is expected that others will be approved shortly.

BiPAP® Systems and CPAP are assist devices and are not usually used for life support ventilation.

**Portable volume ventilators** deliver a preset volume of air (the bi-level pressure devices do not). Ventilators can deliver breaths at chosen intervals, whenever an individual wants an additional breath, and synchronized with the individual's breathing effort.

PVV, PLV-100, and PLV-102 are portable volume ventilators manufactured by LIFECARE International, Inc., Park Centre, 1401 West 122nd Ave., Westminster, CO 80234-3421 (800/669-9234).

LP-6, LP-6 Plus, LP-10 are portable volume ventilators manufactured by Aequitron Medical, Inc., 14800 28th Ave., N., Minneapolis, MN 55447-4834 (800/497-4979).

Bear 33 is manufactured by Bear Medical Systems, Inc., 2085 Rustin Ave., Riverside, CA 92507-2437 (800/232-7633).



# Vignettes... of Polio Survivors Using Ventilation Assistance

◆◆ In 1950, I was completely paralyzed by polio. I spent six months in the iron lung, but slowly through therapy I reentered life unable to lift my arms.

Post-polio respiratory weakness was a phrase I did not like to hear, thinking that my chest cuirass which I used at night would be adequate. I was wrong. I had heard speakers discuss positive pressure ventilation and masks at the G.I.N.I. conferences but as an active individual, teaching three grades in a private school, doing family things, going on vacations, participating in church activities, I just did not have time to think morbid thoughts about respiratory collapse.

The body can be pushed only so far and at 42, you are not what you were at 16 (even without polio). Push came to shove. I became weak so I pumped more vitamins and iron pills. After reporting dizziness one summer to our local physician, I was treated for inner ear problems, although my ears looked clear. Being an optimistic person, I refused to admit that there was a serious problem and knew I would be better in the fall when it was cooler. I was getting older, you know.

While visiting the dentist, I had to leave the chair and the building, because I was so claustrophobic and dizzy. I began to have trouble breathing when I brushed my teeth. Other things began to happen. I would actually fall asleep in the classroom helping the children with their work. They would scamper off to get me a cup of coffee to help me stay awake.

My Amish-Mennonite family of five sisters and five brothers came to my rescue. My sisters saw my dilemma better than I. They literally forced me to seek medical advice. I was referred to Dr. Edward Sivak who understood my problem and suggested a nasal mask over the phone. I tried to convince him that I only needed a better fitting cuirass. He very patiently listened and made an appointment for me. (Edward Sivak, MD, is now at SUNY Health Center in Syracuse, New York.)

I will never forget the first time I tried the BiPAP® System and the mask. I was afraid of it. I immediately jerked the mask off my face when I felt the air. In my heart I knew it was either this or a tracheostomy. I did not want a trach.

Once I quit fighting the mask, and accepted it as a friend, it began working. Now I look forward to putting it on at night. I just let the air enter my nostrils and soon I am asleep. This took at least two months to happen though.

I no longer have those severe headaches at the base of my neck in the morning, no abnormal sleepiness during the day, no swelling of the ankles. My color is very good, and my strength is back. I have a zest for life. *Vera Overholt, Minerva, Ohio*

◆◆ I had polio in August, 1949, and was completely paralyzed. Within hours after admission to the hospital I was placed in an iron lung where I remained for two and

one half months. After recovering with weakness, I did not have any other breathing problems until I had surgery in 1984, and after that I had yearly exams by a pulmonologist. In 1990, following surgery, I went into respiratory arrest. Since that time I have used the BiPAP® S/T at night with a Sullivan Bubble Mask. It lowered my CO<sub>2</sub> and made it possible for me to return to the working world.

I have had some problems with a pressure sore on the bridge of my nose. When the pressure becomes too bad I use ADAM nasal pillows by Puritan-Bennett for a week and then go back to the mask. I find the pillows uncomfortable, and do not like the rush of cold air going up my nose. If I have any air leaks around the mask, I just put some cotton under the leaking area. A mask that fits comfortably is important in adjusting to BiPAP® System. Also, don't fight it — try to relax and let it help you breathe — you will feel so much better. *Sheila Stuckey, Cincinnati, Ohio*

◆◆ My three-month hospital stay in 1952 included six weeks in an iron lung. I have complete paralysis of one arm and weakness in the other, plus some additional weakness in the shoulders and upper back, but I had no respiratory problems until 1980. Beginning with IPPB treatments using Provental on a Bennett AP-5, I had to add night-time ventilation — first with an Emerson Poncho Wrap and then in 1987 with a Bear 33. I use a custom-made, acrylic face mask that has no straps or bands. It is held in place on my face by a bite-wing type mouthpiece. (The mask was made at Dallas Rehab Institute by Sue Sortor Leger, RRT, now in Lyon, France.) I can get in and out of it independently despite the limited use of my arms. I sleep on my back or side and can move comfortably at night.

The Bear 33 has a deep-breath sigh cycle which has been most beneficial. Having an AP-5 in my school classroom and a Monaghan with cigarette lighter adapter for in-car IPPB treatments has allowed me to keep teaching and attending workshops, etc. Since I drive 35 miles a day to school, I "rest" on my Bear 33 with a pipe mouthpiece, again using the cigarette lighter adapter for power while traveling. (I steer the car with my left leg by placing it in a yoke and moving my leg to the left or right as needed.) *Jean Graber, Pretty Prairie, Kansas*

◆◆ I contracted polio in August, 1953, and was in an iron lung for approximately four months. I was left with severe paralysis of both arms and a drop foot on the right leg.

I began using a Thompson Maxivent, a negative pressure unit with a fiberglass/plastic shell over my chest in January, 1984, after a bout of pneumonia. This unit did the job, but was uncomfortable, difficult to travel with, and required constant adjustment of the padding on the shell to keep it sealing properly.

I converted to a Respironics BiPAP® System in March of 1992. I use the standard Respironics silicone contour mask, size medium small, without the mask support ring

continued on page 10

and with a number 6 spacer. I use the unit with the humidifier placed on a small heating pad every night while sleeping and sometimes during the day when I lie down.

For pressure sores on the bridge of my nose, I tried many different masks, finally going back to the original. I now cut most of the adhesive ends off a band-aid and put it on the bridge of my nose every night. This, combined with careful tightening of the mask and routing the air hose up over my forehead seems to keep the pressure sores at bay. Routing the hose over my forehead also seems to stop air leaks around my eyes without having to tighten the mask excessively.

My mouth and nose were very dry in the morning, but the humidifier has reduced the problem. My problem with a runny nose has become less severe, but I still have to blow my nose a lot for the first hour after I get up. Periodic diarrhea, possibly due to ingested air, is still a problem. Since I never know when it may occur, I take an Immodium pill the day before important activities and cross my fingers.  
*Allan Gouldburn, Whitby, Ontario*

◆◆ **I had polio in 1952**, was hospitalized for three months, partially paralyzed in one arm and one leg. I also was left with kyphoscoliosis, but no pulmonary difficulties. In 1981 I had a spinal fusion with Harrington rods. In 1984 I began having noticeable pulmonary problems (in hindsight), but did not recognize them until pulmonary failure hospitalized me again in 1985.

I have been on nocturnal ventilatory assistance for sleeping since then. I progressed from chest shell to pulmowrap to intermittent positive pressure using LIFECARE's PLV-100 and a Respironics nasal mask. The early Respironics masks leaked badly and abraded the bridge of my nose. I used one inch surgical Microfoam tape on my skin for a seal and cushion.

After the G.I.N.I. conference in 1989, I had my dentist make a fitted hard mask with a bite plate, which I used for several years, but it always leaked badly around the swivel fitting because I need such high pressures. It finally became unsatisfactory.

After the G.I.N.I. conference in 1994, I began using the newer Respironics fitted mask with cushion, which is OK, but using the Microfoam tape with it is even better. I have not been able to adapt to a lipseal for oral use, nor could I use nasal pillows. I expect to try a custom mask in the near future. I find that respiratory therapists do not know how to find optimum settings for a ventilator or mask, and use trial and error. I had a sleep study in 1993 which should be part of any evaluation of the late effects of polio.  
*Alan D. Fiala, PhD, Falls Church, Virginia*

◆◆ **Since contracting paralytic polio at age two** and being hospitalized for nine months, I have had slight scoliosis, a slightly shortened left leg, and a totally flaccid right arm. About ten years ago, I developed profound muscle weakness in my left arm. Not having had bulbar polio, I never expected to have respiratory difficulties. However, about two years ago, at age 45, increasing upper body weakness made sleeping, speaking, and even breathing dif-

ficult. A Respironics BiPAP® S/T for night-time ventilatory assistance has given me considerable relief.

After months of experimentation I have settled on a couple of different masks, alternating them for comfort. Most of the time I use a triangular, soft rubber Sullivan Bubble Mask with 2-3 foam rubber spacers at the temple. Two wire twisters from plastic sandwich bags help secure the soft bubble portion of the mask to its hard plastic shell eliminating annoying air leaks when I turn my head.

Occasionally, especially if I want to read in bed, I use the T-shaped Healthdyne mask with nasal pillows since it covers less of the face and obscures less of my vision. I am troubled by mouth and nasal dryness even though I use the Respironics humidifier. Putting a heavy cream moisturizer inside my nose at bedtime and using the Sullivan mask certainly reduce the dryness problem. Despite the nagging inconveniences of the BiPAP® System and its accessories, I am highly enthusiastic about having it and use it faithfully, even when I travel. I view it as an orthotic or brace for my respiratory muscles, thus prolonging their ... and my ... life. *Patti Strong, California*

◆◆ **At the onset of polio in 1953**, I was totally paralyzed, and have remained a quadriplegic since that time. My first six months were spent in an iron lung, followed by using a rocking bed for three months. I used no respiratory aid for 14 years, during which time my respiratory functions gradually deteriorated resulting in severe underventilation, and, eventually, respiratory failure, which landed me in intensive care. Then it was back on the rocking bed for about 12 hours a day, supplemented by using a Bennett AP-4 IPPB (intermittent positive pressure breathing) with a mouthpiece at regular intervals the rest of the time. This arrangement worked well until about 10 years ago when I again began to notice symptoms of nocturnal desaturation.

For the past seven-plus years I have been successfully using LIFECARE's PLV-100 with a Respironics silicone contour nasal mask at night. By placing a small piece of chamois with hypoallergenic tape over the boney part of my nose, I have avoided any problems with pressure soreness. The headstrap required some experimentation and I use a hybrid. It consists of two velcro-fastened straps — the top one goes around my forehead, the bottom one below my cheekbones — attached to a soft piece of flannelette to pad the back of the head. Using a satin pillowcase enables me to turn my head easily during the night without shifting or dislodging the mask.

During the day, I use a mouthpiece with either my PLV-100 or my old Bennett AP-4 as frequently as is necessary to breathe comfortably. If I am going to be away from home more than 4-5 hours, I take my PLV-100 with me. The auto lighter cable, which provides a power source while driving, is invaluable for traveling! *Yvonne Hudson, Winnipeg, Manitoba*

◆◆ **The equipment firm** seemed unaware that one has to use a humidifier with the BiPAP® System, and I had painful problems with cracked nostrils until another polio survivor figured out why.

The firm's respiratory therapist didn't tell me that the ADAM circuit nasal pillows by Puritan-Bennett came in

various sizes. Again, I found this out on my own and experimented until I found the right size.

*Barbara Carter, Granada Hills, California*

◆◆ I used the lip-seal type mouthpiece which was initially totally unsatisfactory and eventually caused me to permanently lose closure of my front teeth. Now I use ADAM nasal pillows by Puritan-Bennett.

I have become very familiar with the controls of the ventilator so that I can make adequate adjustments in air flow in order to compensate for occasional small leaks. These can be frustrating and difficult to isolate in the middle of the night. *Richard Thamm, Wilmington, Delaware*

◆◆ For pressure sores from the two nasal masks I alternate every few days, I toughen the skin under my nose by applying alcohol, and avoid creams and lotion that soften the skin in areas affected by pressure sores. The BiPAP® System and nasal mask have created sinus problems and increased the amount of mucus. I perform nasal irrigation to release the mucus and prevent it from dripping into my lungs and causing upper respiratory infections (acupuncture treatments help when the mucus secretion is severe). I also use a humidifier and a vaporizer and make sure my filter and tubing are kept clean. To adjust to the air flow and claustrophobic feeling, I use a variety of relaxation techniques, visualize the air flow into my lungs, and hold the top of the mask for brief periods to reinforce my own sense of control. *Linda Bieniek, Chicago, Illinois*

◆◆ Three steps — getting used to the mask, being able to fall asleep, and then being able to remain asleep, against the background of getting the right mask and getting all of the machine settings right — pretty much describes the process of adaptation in my case.

I rushed into the transition from a chest cuirass to a BiPAP® System, trying to force my way during a holiday break. It turned into a major ordeal and after a couple of weeks of uncertain ventilation, mounting sleep deprivation, and erratic progress, I retreated to a modified cuirass for several months. Then I renewed my efforts to make the shift, this time using a gradual approach in which I would typically start a night's sleep with the mask but switch back to the cuirass after a few hours. I used afternoon naps to gain experience adapting to the mask.

The first step is to get used to the mask by spending time on it as well as get the right mask and the right size. My physician recommended that the vendor provide a variety of masks for me to try. Perhaps a "beginner's package" should be made at a beginner's price. I encountered a tendency among therapists to fit me with masks that were too small, whereas a bit too large may be preferable. I have settled on the Sullivan Bubble Mask.

The second step is to fall asleep with the mask. Part of this is just sticking with it. For me, it was also a matter of getting the right settings on the machine. While I had good, general guidance, I had to do the refinements on my own through a lot of trial and error. After making several trial adjustments, one night I slightly changed one setting and immediately had my first good night's sleep. I gather that many physicians and therapists prefer, if not insist, that they determine the settings. My experience may imply that

physicians and therapists are essential advisors and collaborators but polio survivors should take an active role in figuring things out, even if by trial and error, a point my physician agrees with.

I continue to have a difficult time with "parched mouth syndrome," an extreme dryness in which my lips, gums, tongue, roof of my mouth, and the front of my throat are all stuck together, and no saliva is flowing. I constantly wake up and never get a full night's sleep. I have experimented with many things, such as I am now sipping water from a bicyclist's Camel Bak. *David Ronfeldt, Manhattan Beach, California*

◆◆ In 1948, at age 13, polio got me. I went into a two-week coma waking up in an iron lung with a tracheostomy learning that I had the chicken pox and double pneumonia. I was weaned from the iron lung and the trach by March 1949. Life seemed normal to me until 1982 when I noticed breathing difficulties especially while mowing the lawn.

After visiting a pulmonary specialist, I tried several non-invasive breathing devices. The chest cuirass could not be fitted to my scoliotic chest and facial masks were too claustrophobic. My blood gases never normalized on supplementary oxygen. I ended up in an emergency room and was trached.

Getting used to the ventilator was hard at first, but now I fall asleep quickly. Being able to go without the vent for a day allows me to take "vacations" once or twice a month. To help my chronic back pain, I started a neuromuscular re-education/myofascial release program with my doctor's consent. A side benefit has been an increase in breathing capacity allowing for more frequent "vacations."

*A.J. Nadeau, St. Louis, Missouri*

◆◆ I contracted polio in 1953. Within 24 hours of entering the hospital I was given a tracheostomy and placed in a tank respirator. I graduated from the tank to a hospital bed, using a cuirass. Ten months later I was free of any ventilator, my tracheostomy was closed. For the next eight years I used no mechanical ventilator, but then my CO<sub>2</sub> began to rise slightly, and I used a Thompson Zephyr for chest stretching and cough augmentation. A few years later I returned to using a Monaghan and cuirass at night.

In 1984 I experienced a sharp drop in my pulmonary capacity, no doubt due to the late effects of polio. After trying several noninvasive mouthpiece/nasal options with little success, I made the decision to have another tracheostomy. My upper extremity strength is limited, and I could never manage to put on or remove the cuirass by myself, nor the mouthpiece/nasal apparatus with its many straps and snaps. Using trach positive pressure, I can connect and disconnect the ventilator, and get in and out of bed by myself. *Richard Daggett, Downey, CA*, excerpted from *I.V.U.N. News*, Fall 1994 (Volume 8, Number 2) □

**Readers:** If you would like to network with any of the individuals who related their experiences in this article, please contact IPN. David Ronfeldt, of Manhattan Beach, CA, sent an extensive description of his experience of adapting. With his permission, we will share this with anyone who asks.



**NOTE:  
New Address!!**

## Panel Recommends New Preferred Polio Schedule for U.S.

In mid-October, the Advisory Committee on Immunization Practices (ACIP) unanimously recommended a preferred, sequential childhood schedule of two doses of inactivated polio vaccine (IPV) followed by two doses of oral polio vaccine (OPV). There are eight to ten cases of vaccine-associated paralytic poliomyelitis (VAPP) each year in the United States. It is hoped that by giving the IPV before the OPV this number will be reduced by 50-70% or more.

IPV does not cause VAPP and has no known serious side effects and is as effective as OPV in protecting individual vaccine recipients. The preferred, sequential schedule is considered a transitional recommendation en route to an all IPV policy when the threat of importation is lower, and ultimately, to a policy of no vaccine when polio is eradicated.

There has not been a case of wild-type polio in the U.S. since 1979, and in the American continent since 1991. However, 120,000 cases of acute poliomyelitis are reported each year throughout other parts of the world.

OPV is considered by most experts to be the world's most effective single tool in polio virus eradication efforts. It induces intestinal immunity which would restrict spread of wild virus should it be introduced, the vaccine virus spreads in the stool to others who may not have been reached through routine immunization, and it is easy to administer. Aggressive immunization efforts and surveillance programs must continue until polio is eliminated from the world.

The Centers for Disease Control and Prevention (CDC) is firmly committed to the goal of global eradication, even as it seeks to reduce vaccine-associated diseases. The preferred, sequential schedule is expected to be adopted by the CDC, and become policy after details such as the timing of the doses are established. The ACIP also stated that an all-OPV or an all-IPV schedule would be fully acceptable. Parents should be made aware of the polio vaccines available and the reasons why these recommendations are made. The risks and benefits of the vaccines for individuals and the community should be stated so that vaccination is carried out among persons who are fully informed. □

## CALENDAR

◆ **The Late Effects of Polio/What Do I Do Now?**, MARCH 23, 1996, Charleston Marriott Hotel, Charleston, SC. Contact: Jane Condon, P.O. Box 335, Folly Beach SC 29439 (803/588-6438). Speakers: Paul E. Peach, MD, Medical Director, and Robbie Leonard, PT, Roosevelt Warm Springs Institute for Rehabilitation, and Joan L. Headley, Executive Director, International Polio Network.

◆ **Everything Old Is New Again** is the conference theme for the American Occupational Therapy Association, Inc. 76th Annual Meeting to be held in Chicago, IL, APRIL 20-24, 1996. Polio survivors Roberta E. Simon, RN, Nancy L. Caverly, OTR/C, and Joan L. Headley have been selected to present a workshop entitled *Post-Polio Syndrome: An Old Adversary Revisited*. Polio survivors are invited to share their experiences with occupational therapy (and vice versa) with the team. Please send your comments to International Polio Network, 4207 Lindell Blvd., #110, St. Louis, MO 63108-2915.

## Post-Polio Related Research

The United States Army has awarded researchers at Albert Einstein Healthcare Network a \$933,532 grant.

Mary Ann Keenan, MD, Einstein Medical Center's Department of Orthopaedic Surgery and director of the Post-Polio Program, Albert Esquenazi, MD, Moss Rehab's Gait and Motion Analysis Laboratory and co-director of the Post-Polio Program, and John Whyte, MD, PhD, Moss Rehabilitation Research Institute, will use post-polio syndrome as a model to learn how to prevent muscle overuse injuries in military training, in the workplace, and in professional and recreational athletes.

Musculoskeletal injuries are alarmingly common in military recruits and most are due to overuse. Weakness produces overuse, overuse causes further weakness, and both predispose one to injury. The bulk of these overuse injuries occur in the first weeks of training, when recruits are exposed to rigorous physical demands.

Findings may help break the weakness-overuse-injury cycle of muscle abuse by shedding light on the relationship between overuse and trauma, the effectiveness of various interventions, and the potential ability to predict the specific injuries that may result from specific weaknesses. □