

ivun news

An Israeli Experience

Philippe Seguin, Respiratory Nurse

Our experience with home ventilation at ALYN Children's Hospital and Rehabilitation Center in Jerusalem started in 1984, when we received our first ventilated patient using a Dräger ventilator. Today ALYN is the only center providing rehabilitation services for ventilator-dependent children up to age 18. Thirty percent of these ventilator users have returned home using partial or total ventilation. Between 1990-1997, forty-five children discharged home with respiratory apparatus included eight with high spinal cord injuries, five with traumatic head injuries, eight with pulmonary-tracheal injuries, and twenty-four with neuromuscular diseases. These children returned to their homes country-wide, including the territories under the Palestinian Authority.

At ALYN, we assess and treat the children as inpatients, usually referred directly from ICUs and already equipped with a home ventilator. The majority of the children have tracheostomies, but several use BiPAP® systems. The main medical funds and insurance companies usually agree to supply the Companion 2800, 2801 or PLV-100. We also care for thirteen children and young adults with muscle diseases who are ventilated, most using LP6, LP10 or EV 800, 801 ventilators. We use the In-Exsufflator Cough Machine often. An additional group of children and young adults are seen regularly as outpatients in a multi-

disciplinary clinic. The children at home also attend this clinic at least bi-annually. On each visit, the respiratory nurse conducts a full nursing assessment including respirometry and blood gases. Our unit also cares for the children with respiratory problems who attend a day care center in our hospital. These children are all residents of Jerusalem and the surrounding area, including one spinal cord injured boy (C1-2) who comes from Hebron for rehabilitation and respiratory care.



Full-time ventilator user, Igal, paints in his bedroom. Igal, who has limb-girdle progressive muscular dystrophy, was the first of 45 children home ventilated after discharge from ALYN.

The care of the child admitted to the hospital is supervised by a specially trained respiratory care nurse. The family is involved as soon as possible in a planned teaching program consisting of up to ten meetings. The program includes general information on the child, his/her problems, needs, special care, and care of equipment. The major costs of the equipment are usually covered by government medical funds or insurance companies (following accidents). The cost is estimated according to the list of equipment requested by the physician and the respiratory nurse.

In recent years, the medical funds have created home care infrastructures, and we keep in contact with the public health nurses who usually come to the hospital before discharge to learn of the child's special needs. They are the ones making the home visits on a daily or weekly schedule depending on demand and services available. Our national insurance allocates a monthly allowance to the family for the support of the child (except for road accident cases). A voluntary organization loans

equipment such as suction machines, oximeters, etc., to the families for three months or until they receive their own equipment. There are some volunteer groups in different areas of the country which offer respite care to the family. These helpers also receive special training in the care of the child, and they prove to be of invaluable help to the families who care for their ventilator-dependent child day and night. ■

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When the Power Goes Off

James and Bill Craig

Whether it is an earthquake in California, a hurricane in Florida, a tornado in the Midwest, or ice storms in the North, there is no substitute for being prepared, and it is vital to make plans for yourself.

The horrific January 1998 ice storm that knocked out power in much of eastern Ontario, Quebec, and Atlantic Canada brings home the need for personal planning by people who rely on electricity to run the machines that keep them alive. While emergency services can provide some help to some people, "You're responsible for your own safety," according to a spokesman for the Toronto Fire Service. The same sentiment is echoed by ambulance and police organizations.

Electric utilities appear best organized to help, and they should be considered your first line of defense during a power crisis. They keep priority lists of people whose lives depend on electrical appliances, and these lists are updated regularly and consulted automatically by repair crews dispatched during emergencies.

What to Do BEFORE a Major Power Failure

- ◆ Keep a flashlight on hand at all times. Keep a supply of spare batteries.
- ◆ Keep a battery-operated radio available to stay abreast of weather and power conditions.
- ◆ Maintain a cell phone in good working order in case the telephone lines are downed.

- ◆ Obtain some type of emergency lighting that will come on automatically when the power fails.

- ◆ Consider purchasing an emergency generator. Check with camping supply or marine equipment stores.

- ◆ Compile a list of telephone numbers of people and services you may need to reach, e.g., power company, fire, police, ambulance, physician.

- ◆ Arrange with relatives and friends to check on you during an emergency power blackout and to stay with you until power is restored or other arrangements are made.

- ◆ Contact local hospitals and motels/hotels to determine if they have emergency power sources and where you could stay.

- ◆ Make a list of items (ventilator supplies, medicines, resuscitator, humidifier, suction machine, etc.) to take with you if evacuation is necessary.

- ◆ If you live in a high-rise, familiarize yourself with elevators connected to emergency power systems. In more modern buildings in Canada, these are indicated by a red firefighter helmet symbol over the door. A yellow helmet indicates limited emergency power. Check with the building owners as well as the firefighters regarding contingency plans for evacuation.

IF YOU USE A PORTABLE VOLUME VENTILATOR ...

- ◆ Test the internal batteries on a regular basis (once a month).
- ◆ Consider having at least one spare external 12V battery on hand and keep it charged.

- ◆ Obtain a battery cable to connect your ventilator to the external 12V battery.

IF YOU USE A BI-LEVEL POSITIVE PRESSURE AIRWAY DEVICE ...

- ◆ Investigate backup batteries.
- ◆ Obtain an inverter to convert the DC power from the battery to the AC power required by your unit.

What to Do DURING a Major Power Failure

- ◆ Disconnect any ventilator equipment from household power circuits to avoid damage to your equipment from a power surge when the power is restored. Reconnect your equipment only after you are certain the power has been restored.

- ◆ Contact your physician. He/she may prefer to admit you to the hospital during such an emergency.

- ◆ Contact friends and relatives to remind them you need assistance. If there is power in their area, invite yourself over.

- ◆ Contact the power company, ambulance, fire department, or police if you need immediate evacuation. Be sure to let your family know your new location.

- ◆ Listen to the radio to determine hospital locations or shelters that could be helpful.

Tales of Survival

Tom Wagner and Philip Fernandes

We conducted telephone interviews with ventilator users directly affected by the ice storms. Their personal stories help to put a human face on this natural disaster.

NEIL BREWER, JR., a full-time ventilator user who lives in Fredericton, New Brunswick, was without electricity for more than 28 hours. Fortunately, he was able to borrow a generator from a relative until the power was restored. His family wanted to have him admitted to the hospital, but because of a flu epidemic, he did not think this was wise. He told us that he felt comfortable staying at home with the support of his family. Neil says he has learned that one must rely on oneself in such situations because local utilities and emergency services can be overwhelmed. Therefore, he has decided to purchase his own generator, not only because of the ice storm, but also because he has had frequent problems with power failures in the past.

JOHN OXLEY, of Montreal, Quebec, uses night-time ventilation. He lives in his own apartment, but the building does not have an emergency generator. The power was off in his area for five days. A local ventilator equipment vendor was able to supply him with a portable external battery and cable to run his ventilator through the night. The battery needed to be recharged, and his family traveled around the city each day in search of a place that had electricity. However, he was still without heat, and the cold eventually became unbearable. He could not recharge his wheelchair and felt helpless and angry about his predicament. Finally he chose to stay with relatives in Kingston, Ontario. John said he was glad to have family support during the storm, but realized the need to be self-reliant. He intends to purchase a portable external battery and cable. ■

Speak to Me ... Better

Jeannette D. Hoit, PhD

In the last issue of *IVUN News*, I described the speech of people with tracheostomies who use positive pressure ventilators. In this article, I explain how to improve this type of ventilator-supported speech.

Although the speech of every ventilator user is different, there are certain speech problems that are common to many, such as long pauses between phrases, and fluctuations in loudness and voice quality. These problems can be attributed, in large part, to the fact that tracheal pressure typically rises quickly to a high peak, falls rapidly, and remains below the threshold pressure, i.e., the minimum pressure needed to vibrate the vocal folds, for a prolonged period. If the tracheal pressure could remain above the threshold pressure longer, speech might sound more fluent, with fewer pauses and more speaking, and be more consistent in its loudness and voice quality.

However, any modification to tracheal pressure must not compromise ventilation. If our only concern was speech, we would strive to create a tracheal pressure that was relatively low (5 to 7 cm H₂O), but constant. Yet such a tracheal pressure would not provide adequate ventilation, and a compromise must be struck.

My colleague, Robert B. Banzett, PhD, and I have been successful in achieving this compromise in the tracheal pressure waveform by making simple adjustments to ventilator settings so that speech is improved and ventilation is maintained. (Hoit & Banzett, 1997).

One adjustment is to extend inspiratory time (T_I). If someone has

a tidal volume of 1 L and T_I is 25%, the full liter is delivered over the course of 25% of the cycle. For example, in a 4 sec cycle time, the flow would be 1 L/sec. If the T_I is increased to 50%, the liter is delivered over the course of 2 sec, so the flow is reduced to 0.5 L/sec. The tracheal pressure under this lower-flow condition would rise more gradually, and its peak (at the end of inspiration) would be lower. This would allow for more speaking time during inspiration, making spoken phrases longer. Also, because the pres-

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international ventilator
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ALS Update: Jim Ballard

Marcy Ballard

(A brief column on Jim and his mobility solutions appeared in IVUN News, Spring 1993.)

My husband Jim has been a ventilator user since May 1992. A newly-retired San Francisco teachers' union and labor leader, Jim was diagnosed with bulbar ALS at age 68. Told by the ALS experts at California Pacific Medical Center that he would need to use a ventilator at night, but could otherwise lead a perfectly normal life, Jim grasped the hope offered and was trached the next day. He remained in the ICU for three months where he suffered oxygen deprivation while enduring prolonged periods of attempts to wean him from the ventilator.

Jim was assessed for language/speech problems by Yvonne Gordon, the chief speech therapist at Barman Rehabilitation Center at St. Mary's Hospital. She confirmed my own diagnosis of expressive aphasia. His receptive language was intact, and he could understand what was said to him, but he had problems with his outgoing or expressive language. When he wrote notes to his nurses, he would call one of them whose name was Thelma, "Twinkle." He also reversed syllables and mixed up words that had similar meanings and associations. The use of a communication board or a computer was not in the cards as we projected and planned for the time when Jim could no longer talk.

For two years after the trach, Jim could talk, eat, and walk. He had full use of his hands and body.

Then he had problems eating and swallowing, and a barium swallow test made it clear that he needed a feeding tube. Thelma, the LVN who had cared for another person with ALS for five years before caring for Jim, cautioned that Jim needed a G-tube. Not realizing there were differences, I settled for a J-tube. The procedure for placing the J-tube is simple and painless, but the food choices are totally limited to liquids. One cannot cut up an orange or add granola and some raisins for fiber to help improve regularity. (Our family found that unless we, the caregivers, investigated available information, we were reinventing the wheel every time there was a new decision to be made. At that time, we were unaware of IVUN.)

Jim had spent his entire adult life representing working people and concerning himself with those who could not advocate for themselves. He had served on the San Francisco Labor Council and was president of the San Francisco

Teachers' Union and vice-president of the American Federation of teachers. Shortly after Jim was hospitalized, Mike Miller, a community organizer of national fame, organized the Jim Ballard Support Committee, a group of friends and business colleagues, to act as Jim's advocates. They arranged for two insurance companies to cover most of Jim's nursing care and worked on every conceivable problem with and for me.

I have come home (from my full-time job as a senior labor and employee relations analyst at the University of California-San Francisco) and found that bills had been paid by the Committee and anonymous donors. A 35-inch screen television was delivered to Jim one day, another time a masseuse appeared who had been paid to give Jim a weekly massage – for one year.

The Committee and labor groups gave fundraising parties and over

More on ALS

"It's Your Choice," a 26-minute video for people facing the ventilator decision was produced, directed, written, and edited by Ismail Tsieprati, a filmmaker with ALS who uses 24-hour trach positive pressure ventilation. Made in 1991, the video is still available for \$19.95 postpaid (within US) from Valona Productions, 5105 East Los Angeles Avenue, #E178, Simi Valley, CA (California) 93063 (805/527-8557).

Journeys with ALS: Personal tales of courage and coping with ALS, compiled by David Feigenbaum, contains thirty-two stories and one poem written by people with ALS (including Feigenbaum) and their families. Available for \$19.95 plus \$5 shipping and handling from DLRC Press, P.O. Box 61661, Virginia Beach, VA (Virginia) 23466 (757/473-1130, 757/473-1510 fax, dlrc@concentric.net). All proceeds donated to The ALS Association and the Muscular Dystrophy Association.

Tuesdays with Morrie by Mitch Albom (©1997, Doubleday & Co., \$19.95). A sportswriter visits his friend Morrie who has ALS and words of wisdom about life and death.

New England Journal of Medicine, October 1, 1998, contains a special article on ALS, followed by an editorial and a rare family story. All are fascinating and provocative.

□ Attitudes of patients with amyotrophic lateral sclerosis and their caregivers toward assisted suicide. L Ganzini, W Johnston, B H McFarland, S W Tolle, and M A Lee. *N Engl J Med* 1998; 339: 967-73.

□ Assisted suicide and alternatives in amyotrophic lateral sclerosis. Editorial by L Rowland (Columbia-Presbyterian Medical Center, New York). *N Engl J Med* 1998; 339: 987-89.

□ Merian Frederick's story by Carol Poenisch. *N Engl J Med* 1998; 339: 996-98.

the last six years have been able to ensure that we did not lose our house and that I would not end up a bag lady in my old age. We live modestly, but we incurred huge bills for such items like a chair glide and a van equipped with a wheelchair lift. These have been paid by the Committee.

Eventually Jim became frozen, although he can still communicate fury or serenity through his eyes, and he lost his beautiful smile. However, without the Committee and the wonderful nurses, many of whom have been with Jim since he came home from the hospital in 1992 and are part of the family, the quality of Jim's life would be considerably different.

Many people question that Jim, frozen and totally dependent on others, would want to continue to live. There were those at the time Jim was trached who expressed their doubts and who could not understand how anyone could be tethered to a ventilator and want to live. One of our children, a philosophy major, remarked that everyone has a theoretical position on another person's time to die. It is only when the sword of death is over one's own head that we really know our position on dying. Jim has lived to see a granddaughter born. He sees his beloved daughter with whom he has always had a close and enduring relationship several times a year. Anyone who knows Jim or is around him can instantly tell his mood and desires.

I will easily admit that there is a continuing sense of profound sadness to the whole situation. I will also affirm that being alive beats being dead and that Jim is relishing each moment of living. Our whole family appreciates the friendship of all these incredible people who help us to get through each difficult step. I have

learned to accept and to receive, something very difficult for an independent person, and have reached a level of humility that I do not find demeaning. I find it rather uplifting spiritually, as my appreciation of the goodness of life and people has accelerated. ■

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A Happy Anniversary

Ismail Tsieprati

My wife Cheryl and I spent Thanksgiving 1998 (November 26) in Las Vegas, celebrating our 28th wedding anniversary. We have many happy memories of Las Vegas, because we were married there. On our 25th anniversary three years ago, we renewed our marriage vows in the same chapel in which we were married.

November 26, 1998, is another important anniversary for us. It marks eight years since I was trached. (I have had ALS for more than ten years). We had been planning to go to Las Vegas to celebrate that year as well, but we never made it. I woke up the morning of the trip struggling to breathe, and we ended up spending our 20th anniversary in the intensive care unit.

For several years after the tracheotomy, I continued to work as a video producer and editor, with specially adapted video editing equipment I operated with foot controls. When it was no longer possible for me to operate the editing equipment, I focused on screenwriting. I completed a 300-page action-adventure screenplay on a laptop computer with special software and an infrared eye blink switch. I am fed through a G-tube

and communicate by eye blink. I also communicate amazingly well with eye movement and facial expression.



Since I received the trach and began using assisted ventilation at home, Cheryl and I have shared a challenging but happy eight years, enjoying many wonderful times, facing problems, and overcoming obstacles together. To say it has not always been easy would be an understatement. Often, life has been downright hard. We are fortunate to have licensed vocational nurses provide skilled care for me during the day. This enables Cheryl to hold a full-time job and to perform the activities necessary to run the household and coordinate my care. Cheryl provides care throughout the night and whenever a skilled nurse is unavailable.

We could not have made it without a lot of help – from our friends and family; from the many nurses who have become part of our lives and created the best quality of life possible for both of us; and from the wonderful, supportive health care team and the fantastic physicians who have been involved in my care.

Would we do it all over again? You bet we would. The ventilator has enabled us to be together these past eight years. We look forward to spending many more years, many more anniversaries and Thanksgivings, together. ■

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sure changes are more gradual, the loudness and quality of the voice would be more even.

There are some disadvantages in extending T_I . Because it is possible to speak longer during inspiration, there is more opportunity to divert air through the larynx and away from the lungs. Thus, pulmonary ventilation may be reduced, and the speaker may begin to feel breathless. There are easy solutions for this. The speaker can close the larynx for a few moments so that all inspired air is routed to the lungs enabling the speaker to catch a breath, and/or tidal volume can be increased to compensate for the extra air lost through the larynx. Another disadvantage is that if T_I is too long, there may not be enough time to expire fully before the next inspiration, and T_I would need to be shortened again.

A second type of ventilator adjustment that is useful for improving speech is positive end-expiratory pressure (PEEP). Many home ventilators do not have PEEP control, but it is easy to attach an external PEEP valve to the expiratory line of the ventilator. PEEP is designed to hold pressure in the ventilator system so it does not fall below a given level, e.g., if PEEP is set at 5 cm H_2O , pressure should not fall below 5 cm H_2O .

Adding PEEP can prolong speech by keeping tracheal pressure above the threshold pressure for a longer time. PEEP can extend the time spent speaking during the expiratory phase of the breathing cycle, whereas increased T_I can extend the time spent speaking during the inspiratory phase.

A disadvantage of PEEP is that it can increase intrathoracic pressure and impede venous return, so there are certain people who should not use it. Nevertheless,

the PEEP levels we use to improve speech are quite low, 5 to 10 cm H_2O . It is important to have a relatively good stomal seal for PEEP to work for speech.

Combining these two adjustments – extended T_I and PEEP – has proven to be especially effective. Speech tends to be more fluent, louder, less variable in loudness, and more pleasant in voice quality. Most ventilator users have told us that this combination of adjustments is comfortable for breathing, in some cases even more comfortable than their usual ventilator settings.

Ventilator users who want to try these adjustments, should do so ONLY with the approval of their physician. There may be medical reasons why one should not adjust the ventilator in these ways. The advice of a speech-language pathologist in collaboration with a pulmonologist or respiratory therapist can assist in determining the best adjustments for both speech and ventilation. ■

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Reference

Hoit, J., and Banzett, R. (1997). Simple adjustments can improve ventilator-supported speech. *American Journal of Speech-Language Pathology*, 6, 87-96.

Traveling with a Child with a Trach

Priscilla Thibault, MD

Our daughter Clarice, now 2½, has had a trach since she was 5 weeks old. She has Pierre Robin, a craniofacial disorder consisting of a cleft palate, small lower jaw, and abnormal tongue position that can block the airway.

Traveling by airplane is difficult because we have found that airlines are used to dealing with people in wheelchairs. They do not know how to deal with a trached infant or child who has two suction machines, a nebulizer, a monitor, a carry-on bag of supplies, and a diaper bag with even more supplies. We have been treated rudely and rarely received the assistance we required. Our travel agent designated Clarice as needing a wheelchair and that helped somewhat, because then someone usually showed up to help.

For traveling, I would recommend taking two portable suction machines. Although we have never had one break down, it is reassuring to have a backup, and you can leave one plugged in and charging while you are using the other. We have a special carry-on bag that I keep packed at all times (our hurricane bag) with about two weeks of trach supplies. I pack a small dishpan, useful for soaking parts, in a separate bag with the nebulizer and the monitor which fits into the dishpan.

If you travel with suction machines, monitors, etc., allow extra time for the security check, because you may be asked to plug in each piece to prove that it is "live" electrical equipment. ■

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Education and Ventilator-Assisted Children in Japan

Yumiko Yoskioka

Yumiko's daughter has been in a semi-coma and mechanically ventilated for six years.

In Japan, it is very difficult for children with disabilities to get into a regular school system. In the Baku Baku Club, there are 46 children with Werdnig-Hoffmann disease and only six of them attend regular school. Most of these children use ventilators continuously. There are 24 children with Ondine's curse who use ventilators at night, and they are able to go about by themselves during the day.

The children are treated the same in the educational system, even though the two diseases cause very different limitations in the children's activities of daily living. They are forced to attend special schools instead of nearby regular schools; their parents are requested to accompany them to provide their special respiratory care.

Unfortunately, school principals place the priority on job security, rather than acceptance of a high-risk child. Our Baku Baku children face considerable obstacles in the outside world. It is difficult to change society's attitudes, but we continue to jump into local society and spend time with nondisabled people.

The majority of Japanese people still view the ventilator as a fearful symbol of emergency or terminal care, strongly connected to death. For us parents, ventilators assist in daily life, making it more comfortable and convenient for our children. ■

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Saki's Story

I was born in 1982. I have Werdnig-Hoffmann disease and use tracheostomy positive pressure ventilation. I attended kindergarten through elementary school in a wheelchair. When I was in my second semester of seventh grade, it became difficult for me to sit up. Now, I study on a stretcher in the classroom, accompanied by my mother.

I am a 16-year-old high school student who wears pierced earrings and make-up just like everybody else. But I have one thing different: I breathe through a hole in my neck.

Two years ago, I resisted the tracheotomy. But my doctor told me that if I did not get a tracheotomy, I would go to sleep deeply forever. I am too young to die, so I decided to do it. When I woke up after the operation, I saw my mother's face and thought that she was an angel. Her tired and old face was full of anxiety. I could not see clearly because my eyes were full of tears.

I could not communicate with my mother, and I became irritated when she did not understand me. I felt uneasy. How could I go on living in my future? But after six months, a miracle happened to me. I could speak with my voice again. I could speak better and better every day as an infant learns to speak words. This was a surprise for my doctor.

With my speech back, I couldn't stay still. I knew I could go to junior and senior high school. I had to take entrance examinations for each school. When a school turned us down, my mother's face was like the great King Yama (the King of Hell), and it was also filled with sadness.

I made up my mind to go to the Hakata Seisho High School. My mother agreed with my decision. We discussed with the teachers how my school life would be. The principal said to me, "We would like to welcome you to our school because of your high potential, not your disability." I was so happy to hear these words.

I do not want to overwork myself, so I am planning to graduate in five years. (It usually takes three years to graduate.) I take a break once a week, and I intend to get 16 units a year. Each class is one hour and thirty minutes. It is a little long. Each student chooses subjects according to his/her future course of study. We are not forced to take any subjects we don't like, unless it is a required subject. We can make our own class schedule. It is a rare high school system in Japan, more like a university.

I travel to school in my mother's car. It is about an hour's drive on the highway, which is the only time to talk with my mother. But she has to concentrate on her driving, so she does not answer much. My mother attends classes with me and takes notes for me. She makes a lot of mistakes in words. I wonder why she makes so many mistakes when she is only copying. During lunchtime, we go to the health office at school, where I eat lunch at a slow pace. I lie on a bed there, because I get tired from lying on a small stretcher for a long time.

English is my favorite subject. My teacher and I exchange a diary in English. Every day enjoyable lessons are waiting for me. In my high school, there is a homeroom class only once a week. We have term examinations four times a year. I take the examinations in a special room by myself. This is

CONTINUED ON PAGE 8

the worst time in school. During the examination, I say the answers, and my favorite teachers write them down for me.

After school, I take a private computer lesson. Recently I started to use the Internet, but it takes much time to operate. I want to make my own home page.

The drive home from school also takes one hour. When I get home, I do my homework. Soon the clock points to twelve, and I must go to bed. In this way, my days end. I feel that I discover new things every day and I live a full life day by day. My heart is throbbing with expectations. When I graduate from high school, I want to go to college. My big wish is to go to Disneyland in America. I am going to study English harder so that my dreams will come true. ■

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IVUN Resource Directory 1998/1999
is an excellent networking tool for health professionals and both longterm and new ventilator users. Sections are dedicated to health professionals, ventilator users, equipment and mask manufacturers, service and repair, organizations, etc. The cost is \$5 USA; \$6 Canada, Mexico, and overseas surface; \$7 overseas air. (US funds only)



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