

# POLIO NETWORK NEWS

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## Let's Talk About Oxygen and Polio

Roberta Simon, R.N.

Many myths and truths are circulating in polio circles about oxygen use in medical crises. This is causing great apprehension for many, especially those that had bulbar polio. I think it is time to clarify some of these misunderstandings.

Let's start with a quote from the *Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors* published by Gazette International Networking Institute (G.I.N.I.) in St. Louis. (As far as I'm concerned this is must reading for all polios whether they have the late effects or not!) Under "Oxygen" it states, "oxygen should be used with caution. In the face of hypercapnia, oxygen therapy may eliminate the final mechanism for maintenance of respiratory effort and thus result in apnea. Maintenance of adequate alveolar ventilation is of primary importance. In case of severe hypoxia and respiratory failure, mechanical ventilation and oxygen may be necessary." Now that we have all of that technical information let's dissect it so we can digest and understand it!

First, we must understand hypercapnia. Hypercapnia is excessive (more than necessary) carbon dioxide in the blood. This value can be determined by taking blood from your artery (not your vein as is usually done) when you are admitted to the hospital or when your physician sees a necessity to determine this value, such as prior to surgery.

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## "Prescription for Weakness" from Fifth International Polio & Independent Living Conference in Saint Louis

Polio survivor, Marny Eulberg, M.D., Mercy Medical Center, Denver, CO, moderated the session on weakness. The presenters were: James C. Agre, M.D., Ph.D., Director of Post-polio Clinic, University of Wisconsin Medical School, Madison, Wisconsin; Daria A. Trojan, M.D., Montreal Neurological Institute & Hospital, 3801 University, Montreal Quebec H3A 2B4, Canada; Jacquelin Perry, M.D., Chief, Pathokinesiology/Polio Service, Rancho Los Amigos Medical Center, Downey, CA. The comments of Dr. Agre and Dr. Trojan (who works with Dr. Neil Cashman and Dr. Daniel Gendron) are printed below. Dr. Perry's remarks will be published in a future issue of *Polio Network News*.

**DR. EULBERG:** A woman in our clinic summarized the problem of weakness very superbly when she said, "Stairs and curbs are getting higher, chairs and sofas are getting lower, and my shoes are getting heavier!"

Weakness is a symptom that comes on slowly, and we polio survivors may be unaware of it. Then one day, we can no longer push ourselves to perform in the way we had in the past, or we begin to fall, trip, or drop things too many times. As a professional, I can suggest techniques or prescribe assistive devices that can be used to compensate for these weaknesses and keep someone functioning. As a polio survivor, concerns about the new weakness sometimes prey on my mind. How much weaker will I get? Am I going to be able to keep on working? Should I change jobs to one that is less physically demanding? What about recreation? Should I forget about that white water raft trip down the Grand Canyon? Should I make plans to do it in the next year or within the next five years?

I'm sure many of you have had similar questions. Are these fears rational or irrational? Today we will attempt to answer some of these questions.

**DR. AGRE:** In looking at a prescription for weakness, I would like to briefly discuss a number of issues including how much exercise should be done, why we

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## "Prescription for Weakness"

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should exercise, and what are the possible causes for decrease in strength and endurance in polio survivors. During this, I would like to review some of the research that we are doing at the University of Wisconsin and reach some conclusions about exercise.

What should be considered exercise? Is running in a long race exercise? Is an individual in a wheelchair participating in a ten kilometer race exercise? Is daily activity exercise? I'm not going to be able to answer that question for you, but I believe that all of the above should be considered exercise.

Why should we exercise? Exercise has long been advocated as something that brings on good health.

It can help reduce blood pressure and heart rate; increase work and cardiorespiratory capacity; increase muscle strength and endurance; reduce blood coagulability; affect insulin production levels and increase your HDL cholesterol. (An increase in the HDL cholesterol appears to reduce the risk of heart attack.)

Exercise may also lead to a number of psychological benefits, although these benefits are difficult to measure. All of us know that a routine exercise program can relieve muscle tension and, if you're not overdoing, make you feel better and sleep better. It might aid in the motivation of other health habits such as weight reduction, cessation of cigarette smoking, and dietary changes.

The importance of good nutrition and health is also becoming common knowledge. I would recommend cutting down on saturated (animal and some tropical oils) fat. Also an increase, rather than a decrease, in the carbohydrate content of your diet is important.

This is another way of decreasing fat. (Shy away from diets that are low in carbohydrates because you will be getting a high fat diet.)

There can be many adverse effects from limited activity. Deterioration in cardiovascular performance plus reduction in strength and in flexibility are among some of the possible problems related to inactivity. Other problems include metabolic disturbances and an increase in anxiety and sympathetic nervous system activity. Maintaining ideal body weight is certainly more difficult when one is inactive.

There is some suggestion that an increase in physical activity can help reduce anxiety. Many people have concluded that sport or activity will increase the years of one's life. That's a debatable issue. More importantly, activity can enhance the quality of one's life and add life to the years (even if it doesn't add years to the life). Quality of life issues are very important. For instance, one doesn't have to be extraordinarily active to see and enjoy a pretty sunset.

Let's look at some of the factors that might lead to the perception of decrease in muscle strength and endurance and fitness. One factor is not being aware of how much loss people had early in their polio. It's very hard to be aware of how much strength one had or has.

The aging process can lead to decrease in strength and endurance and fitness. The peak is reached somewhere around the age of 20 or 30. Aging is an inevitable process and with aging there can be a decline in function.

Weight gain can cause problems. Over half of our clinic population who complain of problems with ambulation and stair climbing also acknowledge that they have gained a lot of weight.

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Poor nutritional habits can also cause problems with strength, fatigue, and endurance. I know survivors who don't eat a good breakfast (or not at all). They may have a cup of coffee. For lunch, they have a salad and diet drink. Their main meal is dinner, but unfortunately they crash at two in the afternoon. Some of that could be depletion of carbohydrates. Loss of carbohydrate stores can cause fatigue and can affect muscle function.

Both under-activity and over-activity can cause problems. Under-activity leads to deconditioning. Over-activity leads to overuse problems. Problems with muscle pain and joint pain can get progressively worse if you try and push through it. I think the prime example of over-activity was provided by our U.S. Olympic Committee in 1984 when we had our marathon trial about two to three months before the Olympic marathon. The gentleman who was supposed to win the race took first place in the U.S. trial, but then in the Olympics he crashed and burned. He hadn't recovered from the Olympic trials and he is, of course, a world-class athlete.

Eric Mueller looked at decrease in muscle strength with immobilization. He measured the strength of the biceps muscle of a group of 24 young and healthy individuals and put them in an arm cast to immobilize the muscles. He took the cast off at seven days to measure the strength, and then did the same thing at fourteen days. At seven days these healthy individuals lost over 20% of their strength on the average. Immobilization can certainly cause significant weakness very quickly.

Poor pacing can certainly lead to problems with decrease in strength and endurance. Muscle energy stores increase with rest and decrease with activity. With rest the energy stores become somewhat repleted; with more exercise, more depletion; repletion with rest; depletion with further work. By pacing yourself, you can keep the energy stores within the muscles from becoming exhausted.

Our research is sponsored by the Easter Seal Research Foundation. The questions we wanted answered were: 1) Is there a difference between symptomatic and asymptomatic polio survivors in strength? 2) Is there a difference in endurance? 3) Is there a difference in capacity to perform work? 4) Is there a greater difficulty in the symptomatic polio in recovering strength following exhausting exercise? and 5) Is there a difference between symptomatic and asymptomatic polio survivors regarding evidence of severity of the original polio illness?

We tested individuals who had at least grade 4 strength in the quadriceps. With some resistance, they could straighten the knee against gravity. By taking a history and by EMG testing, the severity of the polio was greater in the symptomatic group. Strength was less in the symptomatic group (60% of the asymptomatic group). However, the endurance time of the muscle was the same in all groups.

We did some electrophysiologic studies of the muscle, and they showed a similar pattern of fatigue and recovery in the muscle. It seems like the muscle is working well, but there's just less of it. Because there's less muscle and less strength in the symptomatic group, work capacity is less.

Recovery was less in the symptomatic group, and we hypothesize that this was due to the reduced number of motor units within the muscles. To study recovery, we noted recovery of strength every 30 seconds the first two minutes, and then minute by minute to 10 minutes post-exhaustion time. The control and asymptomatic groups recovered strength in similar fashion. The symptomatic group, however, did not recover strength as readily as the control group.

Interestingly and importantly, the perception of exertion (how tired the muscle was becoming) was the same in all three groups. That's not surprising, however, because polio really didn't affect sensation. (The polio mainly affected muscle strength by destroying the cells in the spinal cord that control the muscles, the anterior horn cells.) Individuals can perceive how hard it is that they're working, and I think that's a very important factor when we're looking at a prescription for exercise, especially when we see what happens when symptomatic polio subjects become exhausted; they do not recover strength very well.

We believe that a decrease in strength significantly affects work capacity and the ability to recover strength after activity in our symptomatic polio survivors.

How much exercise should you do? What exercise do you wish to do? The American Heart Association recommends at least three exercise periods per week of 20 to 30 minutes per session. But again, this is in a neuromuscularly intact individual and the heart rate is at a reasonable training rate. You should be able to talk to your friends while you're exercising. You should be able to enjoy it. You have to listen to your body. Your body really does know how much to do. It certainly will let you know when you're overdoing. If you feel fatigued the next day, then you've overdone and you will have to reappraise what you're doing. The exercise should be comfortable, pain-free, and

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## "Prescription for Weakness"

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FUN! If it's not fun, there's really not much point in exercising. By maintaining function one can enjoy life.

### RECENT, RELATED PUBLICATION

"Neuromuscular Function: Comparison of Symptomatic and Asymptomatic Polio Subjects to Control Subjects" by James C. Agre, M.D., Ph.D., and Arthur A. Rodriquez, M.D. *Archives of Physical Medicine and Rehabilitation*, July 1990, Vol. 71. Pages 545-551.

**DR. TROJAN:** New or increased weakness is a major symptom in individuals with post-polio syndrome. Clinically, this weakness is manifested as either a permanent new loss of muscle strength or waxing and waning strength which is related to activity. The latter condition is known as muscle fatigability and is defined as increased weakness on exertion improving with rest.

Currently, the diagnosis of new weakness and muscle fatigability in individuals with previous polio remains clinical. There's no known diagnostic test which can discriminate symptomatic from asymptomatic post-polio survivors.

In an earlier study by our group, (NEJM 1987;317:7-12), it was concluded that abnormalities seen on electromyography (EMG), single-fiber electromyography, and muscle biopsy occurred with equal frequency in both symptomatic and asymptomatic individuals. Both groups showed evidence of ongoing or active denervation. (Denervation is loss of nerve supply to the muscle.) However, more recent data obtained from macro-EMG studies suggests that the cumulative loss of muscle fibers is greater in symptomatic than asymptomatic patients. Macro-EMG is a special type of EMG test which can measure motor unit sizes, or the number of muscle cells a nerve cell supplies.

Survivors with prior polio show evidence of neuromuscular junction communication defects on a special EMG test called single fiber EMG. (The neuromuscular junction is the point where the nerve cell communicates with a muscle cell and causes a muscle contraction.) Similar neuromuscular junction communication defects are seen in other neurological disorders. These defects may be the cause of muscle fatigability which is observed in post-polio survivors and in individuals with other neurological disorders.

Treatment of new weakness and muscle fatigability can take many forms.

First, treatment of any associated medical conditions must be instituted. Some medical conditions may be a

cause of weakness and fatigue, and they should be identified and treated. This is especially important for respiratory dysfunction.

Second, treatment of weakness and joint instabilities can include weight loss, physical therapy, orthotics (braces), mobility aids, and orthopedic constructive procedures. Weight loss, when indicated, can reduce fatigue and reduce the amount of mechanical stress which is applied to already unstable joints. Physical therapy can include stretching exercises along with ambulation and mobility training. Orthotics, or braces, may also be necessary.

I would like to expand upon orthotic management of the more common bio-mechanical deficits. Foot drop during gait is caused by weakness of foot dorsiflexor muscles (muscles which bring the foot up) and is best managed by an ankle-foot orthosis. There are many varieties of ankle-foot orthoses including the cosmetic plastic and the traditional, double, metal upright ankle-foot orthosis.

Second is forward collapse while standing. This occurs secondary to weak leg extensor muscles (found on the posterior aspect of the leg). Usually when this is present only in one leg, no treatment is necessary. However, when both legs are affected, an ankle-foot orthosis can be used. In addition, a cane or crutch may be necessary.

A third problem is genu recurvatum or backward bending of the knee. This occurs because of weak quadriceps or knee muscles (found on the front of thigh) which causes the affected person to bend the knee back as much as possible to lock the knee and prevent knee collapse when standing on that leg. Over time, this can lead to severe backward bending of the knee due to stretching of muscles and ligaments. If not treated, this can cause pain and increased difficulty in walking. When the quadriceps muscle still has moderate strength, a knee brace can be used. In more severe cases, a long-leg brace or a knee-ankle-foot orthosis should be used.

A fourth problem which is common in post-polio survivors is genu valgum or lateral bending of the knee. This occurs secondary to weakness of hip abductor muscles or muscles which move the leg sideways, away from the body. Because of this weakness, a lateral-bending stress is placed on the knee which causes stretching of muscles and ligaments. This can also cause pain and increased difficulty in walking. This is best managed with a knee-ankle-foot orthosis.

The fifth problem is medio lateral (or side to side) ankle instability which occurs secondary to weak ankle and foot muscles. This can be treated with

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special foot orthotics or shoe inserts. In more severe cases, an ankle-foot orthosis may be necessary.

Other treatments of weakness and muscle fatigability in polio survivors are mobility aids, such as canes, crutches, and wheelchairs. Orthopedic reconstructive procedures may also be helpful.

General health measures, such as proper rest, nutrition, and weight management should be instituted.

Frequent rest periods and naps throughout the day may be necessary to combat overwhelming fatigue which may actually produce more weakness.

Exercise can be useful. Aerobic exercise programs have been shown to produce improvement in energy efficiency and work capacity, while attenuated progressive resistive exercise programs have been shown to increase muscular strength in selected muscle groups. This type of exercise program involves progressive increases in the amount of weight lifted, however, a much lower starting weight is used than normally prescribed. Any exercise program should avoid fatigue as this may produce increased weakness. In general, low resistance, high repetition types of exercises are preferable.

Survivors may benefit from psychological support and counselling. Most individuals with the post-polio syndrome have had to overcome a severe disability earlier in life, and they may have difficulty coming to terms with a second disability.

Pyridostigmine, a longer acting medication, may be useful in the treatment of muscle fatigability. However, the more conventional treatments should be used first. Pyridostigmine can improve the communication between nerve and muscle cells at the neuromuscular junction and has been used to treat muscle fatigability and other neurological disorders. We are currently conducting a trial to assess the effect of pyridostigmine on fatigue and post-polio syndrome survivors.

In addition, we are studying the response of neuromuscular junction communication defects in the post-polio syndrome to edrophonium, a short acting medication which improves the communication between the nerve and muscle cells.

So far, 16 individuals have been treated with pyridostigmine. In ten, we assessed neuromuscular junctional communication by single fiber EMG before starting pyridostigmine. The single-fiber EMG measured jitter, an index of communication of the nerve cell with the muscle cell at the neuromuscular junction. (Specifically, jitter is defined as the variability between the time of firing of one muscle fiber and the time of firing

of another muscle fiber when both are being triggered by the same nerve cell.)

Jitter is increased in post-polio survivors. We performed jitter measurements before and after edrophonium injection in ten post-polio survivors with muscle fatigability. Four patients were found to have a significant reduction or improvement in jitter with edrophonium, four patients had no change in jitter, and two patients experienced an increase in jitter with edrophonium.

To measure response of pyridostigmine to fatigue, several indices were computed for all 16 patients before and at least one month after starting treatment. The fatigue symptom scale as described by Hare and co-workers was used. Zero represents no fatigue while 4 represents unbearable fatigue. We also used a second fatigue scale developed by Dr. Neil Cashman. Zero refers to no fatigue or fatigue which does not interfere with activities of daily living. One refers to fatigue which interferes with activities of daily living. Two refers to fatigue which requires rest or sleep greater than 50% of the day.

We also used the modified Barthel ADL (activities of daily living) index which is used by many rehabilitation facilities to monitor effectiveness of treatment. The possible scores range from zero to 100, where zero refers to an individual who is entirely dependent on others for his activities of daily living and 100 refers to a person who is independent in activities of daily living. The mobility index which was used is modified from one developed by Klingaman and co-workers. Zero represents no ambulatory or walking difficulty, whereas a six refers to someone bedridden.

The results obtained for the 16 patients treated with pyridostigmine show that two individuals were unable to tolerate the medication; ten experienced a reduction in their fatigue which was seen as an improvement in fatigue indices; two showed improvement on ADL indices; one showed improvement in mobility index; and one was able to return to work after initiation of treatment. All four individuals who had a decrease or improvement of jitter with edrophonium on single fiber EMG testing also had a reduction in fatigue with the medication pyridostigmine. Four of the six with either no change in jitter or an increase in jitter with edrophonium and single fiber EMG experienced no change in fatigue with pyridostigmine. The remaining two with either unchanged jitter or increased jitter with edrophonium and single fiber EMG were unable to tolerate the medication pyridostigmine. Thus edrophonium effect on jitter may

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predict response to an oral medication similar to edrophonium in the post-polio syndrome.

From these preliminary results we conclude that:

1) pyridostigmine may be an effective treatment of fatigue and muscle fatigability in selected individuals with the post-polio syndrome; and 2) response of fatigue to pyridostigmine may correlate with improvement of neuromuscular junction communication defects as seen by improvement on jitter on single fiber EMG testing with edrophonium. Further studies are in progress to substantiate these preliminary results.

In conclusion, treatment of weakness and muscle fatigability in the post-polio syndrome should consist of a multifaceted approach. It can include treatment of associated medical conditions, treatment of biomechanical deficits, general health measures, exercise, frequent rest periods, and psychological support. Treatment of muscle fatigability and fatigue may now also include pyridostigmine but only in certain monitored individual situations. However, if none of these treatments proves to be effective in certain situations, I have always been amazed at my patients' ability to treat themselves and make sure nothing comes in the way of certain things which they insisted on doing!

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## Let's Talk About Oxygen and Polio

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When the carbon dioxide level in your blood is increased, it causes many symptoms including morning headache, fatigue, and confusion of thought. Unfortunately in polios that have fatigue as part of their post-polio problem, fatigue due to hypercapnia is at times difficult to sort out without testing.

Our second problem is to understand why hypercapnia may eliminate the mechanism that maintains respiratory effort. Respiratory effort is regulated by the chest muscles and by the medulla, which is part of brain stem. (Located at the base of your brain, the brain stem may have been affected earlier by polio.) The depth and frequency of breathing is established here.

Now here is the tricky part. If this part of your brain has been functioning at top capacity to assist your breathing since you had polio and it is suddenly assisted by outside oxygen, it gets the message that everything is in order — it says, "Great! I need a rest." And then it goes on vacation! Later, when oxygen is discontinued, there may be a problem getting the respiratory center to function again. Hence, the potential danger of oxygen.

Fortunately, this is *not a problem with all polios!* A daytime study of hypercapnia/hypoxic drive may be diagnostic for individuals at risk. The test may be done in a pulmonary function laboratory. If the test is negative, the problem may also be diagnosed by doing a sleep study to determine if you have central (brain-centered) sleep apnea (cessation of breathing while sleeping).

Sleep apnea occurs in polios if the respiratory center of the brain is weak and shuts down for brief periods during the night when the individual has lost control of his/her respirations. One difficulty that results from this is an increase of carbon dioxide in the blood. Increased carbon dioxide may also occur in polios who have chest muscle weakness and may be controlled quite adequately by resting the chest muscles at night. Chest muscles can be rested by using some type of mechanical assistance such as nasal or mouth positive airway pressure.

Because of possible chest muscle weakness, it is imperative that all sleep studies be conducted in a sleep laboratory. Their equipment monitors the movement of your chest muscles while you are sleeping.

(It should be noted that sleep apnea does occur in people that did not have polio or do not have another neurological condition. This type of apnea is called obstructive apnea and is due to airway obstruction or malformation of the jaw.) Obstructive apnea may also be caused by pharyngeal weakness or lack of coordination of muscle function in people that have had polio. These problems cause obstruction of the airway with subsequent cessation of breathing for short intervals of time several times throughout the night. Obstructive events (or apnea) may also have a central origin.

The *Handbook* goes on to say, "in case of severe hypoxia (decreased oxygen in the tissues) or respiratory failure (failure to breath properly to maintain oxygen in your tissues which is essential to life) mechanical ventilation or oxygen may be necessary. Maintenance of adequate alveolar ventilation is of primary importance." This is an absolutely true

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statement and should not be taken lightly. When you reach this period of crises, you must depend on your physician to help you make decisions.

I think it is important to note that individuals with hypercapnia (excessive carbon dioxide) and apnea (cessation of breathing caused by obstruction, weak chest muscles, or the brain center shutting down) have done quite well following surgical procedures and medical emergencies by being placed in iron lungs or on some other type of ventilation assistance for a short period of time.

All of the above can be evaluated by a knowledgeable pulmonologist and properly equipped sleep study laboratory prior to an emergency situation and should be done if warranted. This is why every polio with respiratory or suspected respiratory weakness should have a complete pulmonary evaluation.

*If you did not have bulbar polio and if you do not have chest muscle weakness, you are not at risk for this problem! Should you need oxygen, it is not a problem. You may be treated and supported through a crisis just as any other individual. However, many people are unaware that they did have mild bulbar polio. It is possible you were never tested for it at the time of your original polio, because only the most obvious cases were diagnosed. Therefore, it is suggested that all polios should undergo pulmonary function screening. These tests should include spirometry, lung volume measurements, and a measure of respiratory muscle strength, such as negative inspiratory force.*

**Acknowledgements:** The author wishes to thank Ann Romaker, M.D., for editing the article and for all her efforts in the past to assist polios. She has been extremely generous with her time both in the Chicago, IL, and the Kansas City, MO, where she now resides. Dr. Romaker has a pulmonary medicine practice and is also responsible for the sleep and pulmonary laboratories at St. Luke's Hospital in Kansas City, Missouri. You may contact her at Midwest Pulmonary Consultation, 4320 Wornall Road, Kansas City, MO 64111 (816/756-2255).

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## The Diagnosis of Under-ventilation Following Polio

G.T. Spencer, FFARCS, Consultant in Charge, Phipps Respiratory Unit, St. Thomas' Hospital, London, England

The diagnosis of underventilation after polio is not very different from the diagnosis of any other condition, but maybe it helps to go through it in order, because it can be confused easily with the underventilation and respiratory difficulties which occur in chronic obstructive airways disease. The distinction is important because the treatment is very different and the prognosis, given proper treatment, is very much better.

Firstly, you must be aware that the risk of underventilation after polio exists and that any other unrelated illness, operation or anesthetic may cause trouble. Secondly, you must listen very carefully to the story. If I ever had to make do with only one diagnostic method, this is the one I would choose to keep. It usually gives more information than any other single indicator.

### SYMPTOMS

I am going to list the various symptoms of underventilation which I have seen in 150 patients with polio over 20 years. Many of them were thought by the subjects who experienced them and even by their medical advisors to be caused by quite different things.

- There has to be some weakness of the trunk often including thoracic scoliosis.
- Loss of energy and a tendency to fall asleep easily during the day.
- General weakness and fatigue often affecting muscles which the subject has not previously recognised to be polio weakened. This is a trap which can lead easily to the condition being missed if assessment is limited solely to muscle strength.
- A feeling that the air in the room is in some way bad.
- Claustrophobia — fear of confined spaces.
- Loss of mental concentration and reduced work capacity. This is often attributed by the sufferer to oxygen lack to the brain, but treatment by oxygen therapy alone is positively dangerous and in several patients led to an acute crisis and respiratory arrest.
- A sleep disturbance which can take various forms. These include difficulty in getting off to sleep with nightmares, waking during the night feeling desperately short of breath which often can be confused with

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## The Diagnosis of Underventilation Following Polio

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or with a headache not dissimilar to that associated with hangover due to alcohol.

■ Frequent chest infections, often with difficulty in shaking off coughs or colds.

■ Waking up with sticky saliva around the mouth.

Of course not everybody has all these symptoms and people can have some of them from other causes. Anyone who has more than two or three has grounds for suspicion and further investigation.

### SIGNS

The signs of underventilation include quiet speech with fewer words per breath when speaking, or difficulty in speaking for more than a short time. A reduction in breath holding time and the obvious use of unusual muscles when breathing, for example, the head, shoulders or arms. Difficulty in or a dislike of lying flat is particularly associated with paralysis of the diaphragm, that is the sheet of muscle between the chest and abdomen during breathing, and the special sign of scoliosis. Cyanosis (blueness of the lips and finger nails) is a very late sign of underventilation and its absence should not be regarded as sufficient reassurance that under-ventilation is not occurring.

### MEASUREMENTS

Now at last and quite low down the diagnostic list we get to measurements.

■ Forced Vital Capacity — Undoubtedly the most important is the forced vital capacity which has to be measured in several positions, for example, lying, sitting and standing where that is possible. Serious underventilation is unusual if the forced vital capacity is over three litres, though it can happen if other problems are present.

■ Pulmonary Function Tests — Unfortunately, in people with weak muscles and low vital capacities following polio, formal lung function tests can be seriously misleading. Many of the measurements, for example FEV<sub>1</sub>, are designed to measure the severity of chronic obstructive airways disease and not underventilation due to a restrictive defect such as muscle weakness.

■ Polycythaemia — This term indicates an increase in the red cells of circulating blood and is commonly part of the body's adaptation to chronic underventilation particularly at night. It is not dissimilar to the polycythaemia seen in mountaineers who acclimatize to life at high altitude and it is interesting that we have

seen several patients with mild post-polio underventilation who got into very serious trouble after spending even a single night at high altitude while on holiday, or on a long overnight aircraft flight where cabin pressure can be reduced to the equivalent of around eight thousand feet.

■ Measurement of the Tension of Oxygen and Carbon Dioxide in the Arterial Blood — While this is the most direct measurement of ventilation, the levels can often be normal during wakefulness by day, only becoming abnormal during sleep. Indeed, as is widely known, underventilation after polio occurs primarily during sleep and to prove that this is happening requires an overnight study of breathing during sleep. This must include a measurement of carbon dioxide tensions which is more difficult to measure reliably from the skin surface than is oxygen tension or saturation and many purported sleep studies can be misleading if both oxygen and carbon dioxide tensions are not measured repeatedly and regularly during the night.

## Treatment of Underventilation by Day and by Night\*

G.T. Spencer, FFARCS, Consultant in Charge, Phipps Respiratory Unit, St. Thomas' Hospital, London

There are at least ten different methods of treatment for under ventilation following poliomyelitis and the method selected must not only be fully effective medically, but also socially acceptable and practical in the home. In practice, all methods can be and are used in the home and I think the best thing I can do is to list each method with a brief summary of the advantages and disadvantages.

### TRACHEOSTOMY AND INTERMITTENT POSITIVE PRESSURE RESPIRATION

This is normally used by people who need mechanical respiratory assistance both by day and by night and is probably the best method for patients with very severe muscular paralysis. Its advantages are that it is exceedingly effective, can be provided by relatively simple equipment which is small and convenient and can be

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attached to or incorporated in wheelchairs. Its disadvantages lie mainly in the tracheostomy which is always a route for the introduction of infection, can erode surrounding structures, and prevent glosso-pharyngeal breathing without an attendant being present to occlude the tracheostomy. Tracheostomy tubes can become blocked; speech is possible with a non-cuffed tube but it is intermittent during the inspiratory stroke of a respirator. Some patients who would undoubtedly benefit by it are reluctant to undergo tracheostomy because they feel that it increases their disability, makes them look even less like a normal person and prevents, for example, the wearing of a collar and tie which, even in these days, many believe to be part of being properly dressed.

### **IRON LUNG OR TANK VENTILATOR**

This is also a reasonably efficient form of artificial ventilation. Its use is normally only justified for people who need artificial ventilation by night as well as for all or some of the day. Modern iron lungs such as the Cape Alligator or Rotator, are quick and easy to get into and out of, and we have recently designed and made one in which self insertion and release are possible for people with reasonable strength in their arms. The disadvantages of the iron lung are fairly obvious: it is very large in size and once inside a nonself-release tank, the user is effectively trapped and needs an attendant to be released. Nor is it easily portable for overnight stays from home.

### **MOUTHPIECE INTERMITTENT POSITIVE PRESSURE BREATHING**

This technique has become increasingly popular in recent years and a large variety of mouthpieces which stay in place during sleep have been developed. It is adequate for those with moderate respiratory weakness, but some of the more severely paralysed find that they can only use it for a limited number of nights in succession and need to resort to alternative devices from time to time. The equipment is small and easily portable, though the technique requires some practice and trial and error before it can be regularly used.

### **NOSEPIECE INTERMITTENT POSITIVE PRESSURE BREATHING**

This is similar to the mouthpiece method and may have advantages in that it is less likely to produce obstruction of the upper airway. Development of adequate nasal masks is still continuing and many can easily produce soreness and discomfort over the bridge of the nose.

### **PNEUMOBELT**

This is the only method which works by augmenting expiration. It is not particularly efficient and consists of a belt applied around the abdomen and lower chest which is intermittently inflated thus squeezing air out of the lungs. It is suitable only for people with paralysed abdominal muscles and diaphragm who need to use it during the daytime when sitting up. They usually need something more efficient at night. The equipment is small and the pump can be attached to a wheelchair. When used over long periods there is some evidence that it produces damage to the lower parts of the lung.

### **PROTRIPTYLINE**

This is a relatively new drug which can be taken in pill form on going to bed. It acts by reducing the length and frequency of periods of Rapid Eye Movement sleep. This is a particular type of sleep which occurs in most people during which breathing is most disturbed. It is only effective for people with relatively mild underventilation and is particularly suitable for people with congenital or non-paralytic scoliosis. It has the great advantage that no equipment is required, but, unfortunately, the drug has quite serious side effects producing constipation and dryness of the mouth. It can also cause temporary impotence in sexually active men. In general, it is rarely suitable for people with poliomyelitis, many of whom have a distressing tendency to constipation anyway.

There is no doubt that all these different methods have a place and an adequate medical centre should have them all available and be able to select whichever one, or combination of several, is most suitable and effective for each individual. Unfortunately, equipment manufacturers prefer making large numbers of one or two types of machines rather than small numbers of a variety and, at present, adequate designs of all these devices are only available in a few countries.

\*ED: These two papers were presented by Dr. Spencer at the International Symposium on Poliomyelitis in Munich on April 7-9, 1988. Reprinted from *I.V.U.N. News* (Fall 1988, Vol. 2, No. 2) which is published by G.I.N.I., 4502 Maryland Avenue, Saint Louis, MO 63108 USA.

### **RECENT, RELATED PUBLICATION**

"The Management of Chronic Hypoventilation" by David A. Strumpf, M.D.; Richard P. Millman, M.D., F.C.C.P.; and Nicholas S. Hill, M.D., F.C.C.P. *Chest*, August 1990, Vol. 98, No. 2. Pages 474-480.

## Home Ventilator Manufacturers

Aequitron Medical, Inc.  
14800 28th Avenue, North  
Minneapolis, MN 55441 7  
1-800/824-7203  
(LP6, LP5, LP4, LP3)

Information and Services are available 24 hours a day.

Bear Medical, Inc.  
2085 Rustin Avenue  
Riverside, CA 92507  
1-800/331-2327  
(Bear 33)

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

LIFECARE  
655 Aspen Ridge Drive  
Lafayette, CO 80026  
303/666-9234  
(PLV100, PLV102, iron lung, rocking bed)

Call or write for the name of one of the 18 representatives in the U.S. or one of the 24 distributors in Asia, the Pacific, Europe, and the Americas.

LIFECARE has purchased Thoma Medizintech, GmbH, Hechendorf, Germany. Renamed LIFECARE Europe, GmbH, this subsidiary plans to manufacture the LIFECARE line of products for Europe and will expand its distribution to the entire European theater.

Puritan Bennett Corporation  
4865 Sterling Drive  
Boulder, CO 80301  
1-800/248-0890  
(Maxivent, Bantam, C2800)

Respironics, Inc.  
1001 Murry Ridge Drive  
Murrysville, PA 15668-8550  
1-800/638-8208  
(BiPAP S/T, BiPAP S)

BiPap is a mask ventilator that delivers two different pressure levels—one during inspiration and another, usually lower level, during expiration.

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

## Response to "Prescription for Fatigue," *Polio Network News* (Vol. 6, No. 2)

Numerous survivors contacted IPN to say that the feature article (edited comments from the Fifth International Polio & Independent Living Conference) on fatigue "described me and was very useful."

Rubin M. Feldman, M.D., FRCP(C), Chairman, Department of Physical Medicine and Rehabilitation, University of Alberta Hospitals, Edmonton, Alberta, Canada wrote the following in response to the article on fatigue.

"My emphasis on fatigue in post-polio syndrome has been long standing. Recently, we have been able to document that fatigue can be managed on an exercise basis by appropriate prescription of physical therapy exercises.

"We had done electromyographic fatigue studies on post-polio muscles to determine whether we were accurate in permitting patients to notify the physiotherapist when they had a sensation of fatigue during exercise. We noted that EMG evidence of fatigue appeared two muscle contractions prior to the patient identifying fatigue in their exercising muscles. This confirmation (electrical evidence of fatigue preceding a patient's perception of fatigue) permitted us to proceed with treatment using non-fatiguing strengthening exercises in the way in which they have been described previously at the Warm Springs Symposia and later post-polio conferences.

"Our Post-Polio Clinic at the University of Alberta Hospitals has treated 110 patients over the past two years. Once able to identify post-polio muscles electromyographically, we have found that the muscles, treated with non-fatiguing strengthening exercises, reacted to exercise in the same way as normal muscles. The strengthening effect occurred whenever muscles had initial strength better than anti-gravity. Muscles, when initially encountered with strength that was anti-gravity or less, demonstrated a maintenance effect on exercise without any future loss in strength. These results showed, therefore, a response to treatment which reversed the trend of progressive weakness.

"In addition, the maintenance effect achieved in both groups at the end of treatment could be maintained up to a five year period, according to our present knowledge, if a home exercise program identical to the level of exercise achieved at the end of treatment was maintained on a three times weekly basis, and if patients are able to adapt to a life style that reduces fatigue.

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"We feel we have a method of treating post-polio muscles, as well as muscles that have been weak as a result of incomplete recovery from polio, in a way which reverses the gradual weakening effect in post-polio syndrome.

"I recognize that this approach to treatment emphasizes exercise, while other researchers have felt that exercise should be avoided. I think that the limiting factor in exercise continues to be the recognition that fatigue must be avoided in the treatment of muscles which have recently become weakened after demonstrating relatively normal function for twenty years following acute polio. Muscles that have been gradually weakened during the intervening years since acute polio, which therefore includes muscles which never fully recovered from polio, can continue to be subjected to exercises without regard for fatigue and without concern that they will demonstrate further deterioration.

"It would appear that differentiation between post-polio muscles and muscles which never fully recovered after acute polio is essential if the approach to treatment in post-polio syndrome is to be effective."

## Americans with Disabilities Act Becomes Law

President George Bush signed the Americans with Disabilities Act on July 26, 1990. This landmark civil rights legislation makes it illegal to discriminate against people with disabilities in employment in the private sector, services provided by state and local governments, public and private transportation, public accommodations, and telecommunications.

The law defines an individual with a disability as anyone with a mental or physical impairment limiting "some major life function." It also includes sanctions for those who discriminate in hiring. Victims of employment discrimination may seek back pay, reinstatement, and attorneys' fees. Businesses with fewer than 15 employees are exempt from the hiring provisions.

Regulations will give the law its teeth and that process will be designated to several agencies: Department of Justice, Equal Employment Opportunity Commission, Department of Transportation, and the Federal Communications Commission. The bill contains five titles, each with differing effective dates and each with regulations to propose.

## A Tenting, Lobbying and Celebration Experience!

*Leah Welch, Minneapolis, MN*

For those of you who don't know me, I had polio in 1949, was in an iron lung for six months, went to a portable respirator at night, and then six years ago went to a positive pressure ventilator with a tracheostomy. This has not prevented me from lobbying at the county and state level in person as well as in letter. However, my federal efforts have all been in letter form, or meeting people here in Minneapolis.

Last winter, because of my concerns about the pca issues, I decided that I needed to attempt to meet people personally in Washington, D.C. So I began to arrange a trip, which I took in June. I recognized that because of my severe allergies to many substances, such as are found in hotels, I needed to look for alternative housing. My answer was TENTING!

I had three major concerns; one — a bed, two — a floor for my hydraulic hoist to operate on, and three — a source of power for all my equipment. I found answers for all three, bought a tent, and looked for camps that had electrical outlets and AWAY I went. It was an exciting, exhilarating experience. I surprised a few camp owners, and may have worried some, when they saw me with my ventilator wanting to camp. One owner supplied me with phone numbers for the nearest hospital! It was a bit tricky, trying to operate a hoist on ground that was not level — even with a wood floor under the tent — but we DID it. It was great waking up to the sound of birds and one morning even to rain.

The camping experience was great, but seeing the Capitol, the House and Senate sessions, meeting the Senators and Representatives and their aids, and being a part of the entire process was even greater. My experiences in D.C. have shown me that when I present my views and perspectives, that people in power will listen. They see me as a constituent, as a real, live person; not a statistic. Sometimes, I think they lose their perspective unless we remind them. This is our country and our problem as well as theirs. I also found that once I had seen it all in action, it was more real to me; the news about the House and Senate and the President all became real.

Just after I returned home from my lobbying efforts, I received an invitation to attend the signing of the ADA bill, July 26. My daughter, Donna Robb, was also invited. That day was an emotionally exciting day. There were well over 2,000 people both inside and outside the gate. The south lawn was filled with rows

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## A Tenting, Lobbying and Celebration Experience

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of folding chairs and wheelchairs, gathered together to witness the signing of the bill.

A bit of humor was added to the occasion when President Bush and First Lady Barbara Bush arrived — everyone stood up (most were in front), and there came a huge roar "Down in front!"

In his speech, the President said what we all know and feel, "it was long overdue, it was a beginning step and there was a lot of work to do." I agree heartily. I have seen many changes over the past 40 years, and as this bill was signed, I realized just how much discrimination I experienced 40 years ago and how much things have changed. There were no financial or social programs for disabled people at that time. Architectural barriers were everywhere, and there were not many people out and about. So times have changed, and this bill is a big step in recognizing and acknowledging that we are part of the nation, that, as Michael Ehrlichman stated at the Minnesota ADA celebration, we are now citizens and have the same rights as everyone else. This is a giant step in our fight for equality.

The Minnesota ADA celebration was another victorious, impressive occasion. Senator Durnberger was honored for the large part he played in bringing this bill to culmination. He was one of its strongest supporters on the Senate Subcommittee on Disability Policy.

Now that the bill is signed, we all need to work for its enforcement. That will not be easy, so everyone needs to be involved.

I urge you all to not only work hard but play hard too, and try the camping — you might like it.

### MOVING?

PLEASE SEND BOTH YOUR OLD AND NEW ADDRESSES TO:

INTERNATIONAL POLIO NETWORK,  
4502 MARYLAND AVENUE,  
ST. LOUIS, MO 63108

...WHEN YOU MOVE. POLIO NETWORK  
NEWS WILL NO LONGER BE FORWARDED  
BY YOUR POST OFFICE.

## Information on ...

### NEW BOOK ON POLIO AND THE SALK VACCINE

*Patenting the Sun* by Jane S. Smith recounts the dramatic story of polio and the Salk vaccine. Smith was a Polio Pioneer who volunteered as a test subject in the Salk field trials. The 413-page book, published by William Morrow, sells for \$22.95 at your local bookstore.

### BRAIN TISSUE BANK

Many survivors have expressed an interest in "donating their body to science." International Polio Network contacted the National Neurological Research Bank which is a brain tissue bank, funded by NINDS and NIMH to be a resource for researchers throughout the USA. Subscribers interested in the "Gift of Hope" tissue donor program may contact IPN for general information and Donor Registration and Authorization Forms.

### NEW STUDY ON THE EFFECTS OF AGING ON EARLY LIFE DISABILITIES

Rancho Los Amigos Medical Center is the site for a five-year study, Late Life Effects of Early Life Disability: Physical, Psychological and Socioeconomic Characteristics Comparisons with Age Matched Controls. This study is investigating the effects of aging on persons who became disabled early in life from a spinal cord injury or polio. This group will be compared with 1) older people who have become disabled later in life and 2) older people without a disability.

No previous study has compared the effects of aging for those persons whose disability occurred early in life versus later in life (from stroke, amputation, etc.). Nor have comparisons been made with the aging changes experienced by "healthy," non-disabled older persons. This study will "weed out" the extent to which an older disabled person's new difficulties are due simply to aging or to a change in the pre-existing disability.

The study is in the data collection stage. As of printing, the study has evaluated 85 polio survivors. The goal is 100-125 and data collection will continue until March 31, 1990. Four groups of subjects over age 50 are included: 1) persons with an onset of polio greater than 25 years; 2) persons with a duration of a spinal cord injury greater than 20 years; 3) persons with a new onset of a disability; and 4) persons without a disability. The matching of the subject groups will

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allow for etiologies of various changes to be hypothesized, i.e. is having a particular problem related to having a disability, having a disability for an extended period of time, or simply resulting from aging changes?

This research is funded by National Institute on Disability & Rehabilitation Research (NIDRR). The Co-Principal Investigator and Project Director is Margaret L. Campbell, Ph.D., Research Sociologist, Rehabilitation Research and Training Center on Aging, Rancho Los Amigos Medical Center, University of Southern California, 7600 Consuelo Street, Downey, CA 90242.

## EASTER SEALS RESEARCH GRANTS AVAILABLE FOR 1991

Research Grants for projects that impact the treatment and management of disabilities are now available from the National Easter Seal Society's Easter Seal Research Foundation.

Trustees of the Easter Seal Research Foundation (ESRF) will meet in March 1991 to review proposals and award grants. The maximum Foundation grant is \$40,000 per year, renewable for a second year. ESRF encourages projects that relate research outcomes to improved rehabilitation services for people with disabilities.

Grant applications are sought from all qualified applicants. Applications must be received on or before December 15, 1990.

For additional information, write to Norman D. Grunewald, Vice President, ESRF, 70 East Lake Street, Chicago, IL 60601.

The 1990 ESRF awarded the following new grants:

*Marita R. Hopman*, Rhode Island Hospital, for a study to determine adults' ability to "read" and respond to infants who are at risk for disability. The study will look at the infants at risk for disability (e.g. babies with Down syndrome) to determine whether they present signals that are more difficult to interpret than those of infants not at risk.

*Carl A. Coehlo, Ph.D.*, Gaylord Hospital, for a study evaluating the communications skills and use of language among head-injured adults. Data gathered will be used to develop practical evaluation and treatment tools for people with closed head injuries and to identify distinct recovery patterns.

*William S. Pease, M.D.*, The Ohio State University, for an analysis of stroke survivors' gait to better understand the natural history of recovery following a stroke.

Three grants were renewed:

*Vincent R. Bonagura, M.D.*, Long Island Jewish Medical Center/Schneider Children's Hospital, to continue a study of immune response genes as they regulate disease-specific rheumatoid factors in juvenile rheumatoid arthritis patients.

*Terry Willkomm*, Easter Seal Society of Iowa, to evaluate consumer response to applied rural rehabilitation technologies that help return farmers to work after disabling injuries.

*Laura F. Meyers, Ph.D.*, University of California at Los Angeles, to continue her work using computer-enhanced language intervention with children with learning and developmental disabilities.

## LEADERS WRITE...

### FROM NEW ZEALAND

"The membership role for New Zealand now stands at 400. Group leaders have been appointed in 17 locations. National Secretariat produces a newsletter four or five times a year which is distributed by the group leaders. We are planning an annual meeting in Masterton in September where a committee will be elected to lead the society into the 1990s.

"Unfortunately, we have not managed to establish a clinic, but this is still requested and required. New Zealand has been undertaking major restructuring in the Community/Hospital areas which has delayed new planning ventures nationally. We will continue to pursue a clinic. In the meantime, there are doctors in Auckland, Hawkes Bay, Palmerston North, Masterton, Lower Hutt, Christchurch and Dunedin who are aware of the problems facing polio survivors." *Phillipa Morrison*, 2/6 Sanders Avenue, Napier, New Zealand.

### FROM AUSTRALIA

"The Post-Polio Support Group and the Neurological Resource Centre have received a grant from the Commonwealth Department of Community Services and Health to produce a booklet on the late effects of polio. The book, entitled "Managing the Late Effects of Polio-Information for Health Care Providers," is intended for all members of the health care professions." *Beth Brodribb*, P.O. Box 493, Hawthorn, Victoria 3122, Australia.

(continued on page 14)



## FROM THE NETHERLANDS

"Our post-polio network is under the umbrella of VSN or the Association for Muscular Diseases in The Netherlands which is subsidized in part by the Princess Beatrix Foundation. We have made progress in making the late effects of polio more widely known in our country. Recently, we have published a brochure to be distributed among our members and health professionals. We are now working on a free leaflet for hospitals, rehabilitation centers, and other places relating to neuromuscular diseases." Carla van den Borg, Rigterskamp 32, 1261 TN Blaricum, The Netherlands.

## Vaccine Injury Compensation

The under-publicized National Vaccine Injury Compensation Program had a deadline of October 1, 1990 for claims filed on injuries which resulted from vaccinations before October 1, 1988. At printing, various organizations were lobbying to extend the deadline. If you suspect your polio was vaccine-caused and have not received information through other sources, contact us.

## New Post-polio Clinic

Port Jefferson, Long Island, NY: Joseph Farrell, M.D., St. Charles Hospital, 200 Belle Terre Road, Port Jefferson, NY, 11777. (516/474-6300).

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## Renewal Notices

The Fall issue of *Polio Network News* will be mailed within the next six weeks, and then we will be back on schedule. Renewal notices were delayed during this time. Individuals needing to renew before December have been mailed their notice.

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## READERS WRITE ...

Dr. Michael Rothman in Boston (617/527-4924) and Dr. Debora Phillips in Princeton, NJ (609/924-1212) or in Los Angeles (213/278-6342) need people to do telephone interviews for a research project in self-esteem. We are seeking articulate individuals with a good telephone voice. All work can be done at home." Dr. Debora Phillips, University of Southern California School of Medicine, Department of Psychiatry and the Behavioral Sciences, LAC/USC Medical Center, 1934 Hospital Place, Los Angeles, CA 90033 USA.

"I had polio in 1944 and was treated at the Hickory Emergency Polio Hospital and at Charlotte Memorial Hospital in North Carolina. Through the nine months we were all together, we developed some very close friendships. We want to have a fiftieth reunion in 1994 or 1995 and ask the help of your network in locating individuals who were treated there. Please ask them to contact Margaret B. (Peggy) Benbow, 341 South Indian Rocks Road, Belleair Bluffs, FL 33540 USA."

"Do you know of other service people who contracted polio while in Korea?" William Gerard, 19 Bates Street, Mendon, MA 01756 USA.

"I developed shoulder pain several years ago due to the constant pounding of thirty-five years of using crutches. Last year I was awarded a patent for a crutch tip with a built-in shock-absorbing system. The construction minimizes crutch-recoil. I now manufacture the tips under the name of PERFORMANCE and will offer them to first-time users for half price (\$12.50 plus \$1.50 shipping)." Thomas Fetterman, P.O. Box 12957-P, Philadelphia, PA 19108 USA (215/232-9041).

"I have two CRE negative pressure ventilators from J.H. Emerson that I would like to sell for \$50.00 plus shipping. If anyone one is interested, please have them contact your office." Write or call IPN, 4502 Maryland Avenue, Saint Louis, MO 63108 USA (314/361-0475).

# Post-Polio Directory 1990

*Please add the following:*

## HEALTH PROFESSIONAL

Mary Ann Keenan, M.D.  
Albert Einstein Medical Center  
Willow Crest-Bamberger Building  
York & Tabor Road  
Philadelphia, PA 19141  
215/456-6051

## SUPPORT GROUPS

John H. Garretson.  
5238 Pocatello Court  
Cape Coral, FL 33904

Post-Polio Support Group of Northwest FL  
Carol Jensen  
104 West Hampton Court  
Niceville, FL 32578  
904/897-5572

Post-Polio Network of Southwest FL  
Post-Polio Support Group of Lee Co.  
Tom Marshall, Jr.  
1846 Powell Drive, Lot # 38  
N. Fort Myers, FL 33917  
813/656-1493

Sarasota Post-Polio Support Group  
Frank Leakey  
5707 Westwind Lane  
Sarasota, FL 34231

West Michigan Polio Support Group  
Fred Carlson  
3219 Giddings SE  
Grand Rapids, MI 49508  
616/243-6468

Poteau Polio Survivors  
Doby Green  
203 Butler  
Poteau, OK 74953

Pittsburgh Area  
Dr. L.W. Gumerman  
28 Unger Lane  
Pittsburgh, PA 15217

Post-Polio Support Group  
Options for Independence  
1095 North Main  
Logan, UT 84321  
801/753-5353

*Please make the following changes.*

## CLINICS

UCLA Neurological Center  
Susan Perlman, M.D.  
Suite B 200  
300 UCLA Medical Plaza  
Los Angeles, CA 90024  
213/794-1212 (new patients)  
213/794-1195 (info & messages)

Younkers Memorial Rehab Center  
Karen Kinker, M.D.  
1200 Pleasant Street  
Des Moines, IA 50309  
515/283-6434

## SUPPORT GROUPS

North Central FL Post-Polio Support Group  
Carolyn Raville  
7180 SW 182nd Court  
Dunnellon, FL 32630  
904/489-1731

Central Fl Polio Resource Group  
March of Dimes/Mona Hughes  
714 E. Colonial Drive  
Orlando, FL 32803  
407/849-0790

March of Dimes  
Western Iowa Chapter  
Mark Slocum  
5701 Hickman Road  
Des Moines, IA 50310  
1/800-627-2412

Donnella Judice  
2317 Kirkman Street  
Lake Charles, LA 70601  
318/494-1759