

# POLIO NETWORK NEWS

International Polio Network

Summer 1990 ■ Vol. 6, No. 3

## 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.

(continued on page 6)

## "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

(continued on page 2)

## Inside This Issue

The Diagnosis of Underventilation Following Polio & Treatment of Underventilation By Day and By Night .....	7
Leaders & Readers Write .....	13
Post-Polio Directory Supplement .....	15

## "Prescription for Weakness"

(continued from page 5)

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!

---

## Let's Talk About Oxygen and Polio

(continued from page 1)

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

(continued on next page)

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).

\*This article, or any segment, may not be copied or reprinted without the written permission of the author.

福

## 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

(continued on page 8)