

Newsletter

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January 2013

Website: ppsupportoc.org

New Arrival

Baldwin and Veronica are pleased to welcome their first grandchild, a grandson named Leo, who arrived in the first week of December. While we will miss his invaluable contributions to our operation, we are inaugurating the new year with a new format using Publisher rather than the more complex InDesign which offered more sophistication than we need; hence the new look.

Editorial Note: We are still seeking contributing writers and suggestions from our readers on ways and topics that will make the newsletter more useful and readable. Feel free to offer opinions. While not all may be incorporated, they will all be given serious consideration.

Email those suggestions to me at renison@cox.net. I want this to be a reflect of YOUR needs. Thanks,

Janet

Prescription for Weakness,

DR. DARIA 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;317:712), 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.

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

Other treatments of weakness and muscle fatigability for 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 counseling. 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.

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!

Editorial Note: This article has been shortened for space consideration. Full article can be read at Post-polio Health International/ Reprinted by permission of PHI and IVN. 1991, Vol. 7, No. 3

A Statement about Exercise for Survivors of Polio

Advising all polio survivors not to exercise is as irresponsible as advising all polio survivors to exercise.

Current evidence suggests that exercises are often beneficial for many polio survivors provided that the exercise program is designed for the individual following a thorough assessment and is supervised initially by knowledgeable health professionals. Polio survivors and

their health professionals who are knowledgeable about the complete health status of the individual survivor should make the ultimate decision on the advisability of exercise and the protocol of the exercise program.

Clinical research studies support exercise programs that are prescribed and supervised by a professional for many polio survivors, including those with the symptoms of post-polio syndrome.

Acute paralytic polio can result in permanent muscular weakness when the viral infection leads to death of anterior horn cells (AHCs) in the spinal cord. Recovery from paralysis is thought to be due to the re-sprouting of nerve endings to orphaned muscle fibers creating enlarged motor units. Recovery is also attributed to exercise that facilitates the enlargement of innervated muscle fibers. For example, some polio survivors regained the use of their arms and have walked for years with crutches. Others regained the ability to walk without the aid of braces, crutches, etc., and have continued to walk for decades.

The increased muscle weakness recognized in those with post-polio syndrome is believed to occur from the degeneration of the sprouts of the enlarged motor units. The premature death of some of the AHCs affected by the poliovirus is speculated to also cause new weakness, and some new weakness is caused by disuse, or a decline in activity or exercise.

There is agreement that repetitive overuse can cause damage to joints

and muscles, but can repeated overuse and excessive physical activity accelerate nerve degeneration or nerve death? This is the crux of the physical activity/exercise debate.

Physical activity is movement occurring during daily activities. Exercise is defined as planned, structured and repetitive body movement.

Therapeutic exercise is conducted for a health benefit, generally to reduce pain, to increase strength, to increase endurance and/or to increase the capacity for physical activity.

Polio survivors who over-exercise their muscles experience excessive fatigue that is best understood as depletion of the supply of muscle energy. But, some polio survivors' weakness can be explained by the lack of exercise and physical activity that clearly leads to muscle fiber wasting and cardiovascular deconditioning.

The research supports the fact that many survivors can enhance their optimal health, their range of motion and their capacity for activity by embarking on a judicious exercise program that is distinct from the typical day-to-day physical activities. These same polio survivors need not fear "killing off" nerve cells, but do need to acknowledge that the deterioration and possible death of some nerve cells may be a part of normal post-polio aging.

Exercise programs should be designed and supervised by physicians, physical therapists and/or other health care professionals who are familiar with the unique

pathophysiology of post-polio syndrome and the risks of excessive exercise. Professionals typically create a custom-tailored individualized exercise program that is supervised for two-four months. During this period, they will monitor an individual's pain, fatigue and weakness and make adjustments to the protocol, as needed, to determine an exercise program that a polio survivor can follow independent of a professional.

When designing a program, these general principles are followed to achieve specific goals and/or maintenance levels.

- The intensity of the exercise is low to moderate.
- The progression of the exercise is slow, particularly in muscles that have not been exercised for a period of time and/or have obvious chronic weakness from acute poliomyelitis.
- Pacing is incorporated into the detailed program.
- The plan should include a rotation of exercise types, such as stretching, general (aerobic) conditioning, strengthening, endurance or joint range of motion exercises.

Polio survivors who experience marked pain or fatigue following any exercise should hold that exercise until contacting their health professional.

Researchers and clinicians cannot make a more definite statement until additional studies on the long-term effects of exercise and the effects of exercise on function and quality of life are undertaken.

Criteria for diagnosis of post-polio syndrome

Prior paralytic poliomyelitis with evidence of motor neuron loss, as confirmed by history of the acute paralytic illness, signs of residual weakness and atrophy of muscles on neurologic examination, and signs of denervation on electromyography (EMG).

A period of partial or complete functional recovery after acute paralytic poliomyelitis, followed by an interval (usually 15 years or more) of stable neurologic function.

Gradual or sudden onset of progressive and persistent new muscle weakness or abnormal muscle fatigability (decreased endurance), with or without generalized fatigue, muscle atrophy, or muscle and joint pain. (Sudden onset may follow a period of inactivity, or trauma or surgery.) Less commonly, symptoms attributed to post-polio syndrome include new problems with breathing or swallowing.

Symptoms persist for at least a year.

Exclusion of other neurologic, medical and orthopedic problems as causes of symptoms.

SOURCE: [Post-Polio Syndrome: Identifying Best Practices in Diagnosis & Care. PHI & IVN, Vol. 19, No. 2, 2003](#)

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Other treatments of weakness and

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Rancho Los Amigos Meeting

Follow-up Discussion—Dr. Barras

Saturday , January 26, 2013

2 pm — 4 pm

Orange County Meeting

FINGER FOOD POTLUCK

Saturday , January 12, 2013

2 pm — 4 pm

Future Rancho SG Meetings

Saturday, February 23, 2013

Annual Pot Luck

Future PPSG of OC Meetings

Saturday, March 9, 2013

TRAVEL SHOW—OC Travel

John Mowbray

SUNDAY, MAY 19 or 26 (TBD)

DR. SUSAN PERLMAN

Donations needed year round! Note that we mention donations but not the amount, as all donations make the OC and Rancho groups possible. Please write checks to Polio Survivors Association and write "Newsletter" in the memo section. Please mail checks to Priscilla Hiers, Treasurer PPSG of OC, 18552 Cork St. Fountain Valley, CA, 92708. Thanks this month go to Dr. Selma Calmes, Bertram Justis, and Cecelia May.

How to contact Rancho Support Group

The Rancho Los Amigos Post-Polio Newsletter is published as a joint venture with the Polio Survivors Association

For add additional information please call Richard at 562-862-4508

Email: RanchoPPSG@hotmail.com

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Agenda ideas for PPSG of OC ????

Please call Aleta at **949-559-7102** or email Priscilla: prisofoc@aol.com

**Post-Polio Support Group
of Orange County**

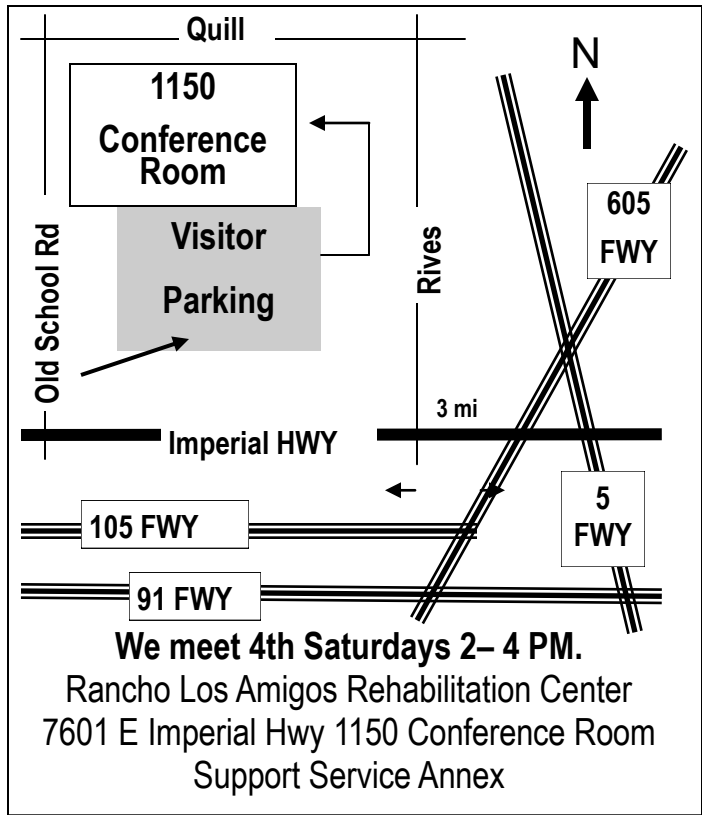
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**Rancho Los Amigos
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