

Founded in 1989  
**The Post-Polio Support Group of Orange County**

15231 Marne Circle  
Irvine CA 92604

# NEWSletter

July 2010

Website: [ppsupportoc.org](http://ppsupportoc.org)

**DON'T MISS** practical post-polio application of the information in our January, March & May **breathing** articles. **Respiratory Therapist** Diana Guth will discuss masks, alternatives, proper use of oxygen. and more on Saturday July 10th (See Pg 8)

## Dr Perlman's presentation to OC and Rancho groups EXCELLENT !

The Vila Park meeting room on Sunday May 23rd was full, however we could have scooted the chairs and wheelchairs tighter and fit in many more. Please mark your calendars now for Sunday May 22nd, 2011 when she plans to give her annual update on PPS research and medical care. In 2011 she is planning on dedicating about a third of her presentation on spinal column stem cell research, particularly the human trials are just getting underway for ALS victims (Lou Gehrig's disease) which, if successful, will indicate that stem cells could be used to replace damaged motor neurons for polio survivors. Dr. Perlman took questions with a great deal of attentiveness and concern. She made every effort to insure that her answers were clear and in vocabulary we could

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understand. There are only a few "polio" physicians in the USA who have the depth of experience and the quest to learn the very latest on polio care research as does Dr. Perlman. She not only provides this high level of care at her clinic at UCLA but also works diligently with primary care physicians and other specialists by exchanging knowledge about the ongoing care of polio survivors. And once a year she shares her insights into post-polio syndrome with us. Many polio survivors in the USA have to travel many hundreds or thousands of miles to hear the type of presentation some of us heard May 23rd. Most of our readers wouldn't have to travel over 35 miles to attend her presentation. Dr. Perlman covered a wide array of issues and her presentation slides are posted on our website: [ppsupportoc.org](http://ppsupportoc.org). In a future issue of the Rancho Los Amigos newsletter **Mary Atwood will provide a written summary of the presentation** and, hopefully, a glimpse at some of Dr. Perlman's answers to our questions. For example:

- What precautions should polio survivors use when taking statins or muscle relaxers?
- How has the current knowledge about activity and exercise affected the old PPS motto "Conserve to Preserve" ?
- How is it possible for some survivors with PPS to gain 1-2% strength and function per year?

**Please view Dr. Perlman's slides on our website. watch for Mary's article, and mark May 22nd, 2011 on your calendar.**

## Exercising With Polio or Post-Polio Syndrome: Prescription for Health

American College of Sports Medicine

Posted: 04/14/2010

### Introduction

The last major polio epidemic occurred more than 40 years ago, but if you contracted and recovered from the disease, chances are you continue to experience symptoms of fatigue and muscle and joint pain. The good news is that physical activity has been shown to significantly increase lower-extremity strength and aerobic capacity. Furthermore, regular exercise can help you maintain your weight and reduce your risk of developing other diseases. The key to maximizing the benefits of exercise is to follow a well-designed program that accommodates your individual needs and concerns.

### Getting Started

- Talk with your health care provider before starting an exercise program and ask for specific programming recommendations.
- The goals of your program should be to improve mobility, your ability to perform activities of daily living, and your overall fitness.
- Choose activities you enjoy and that are within your functional capabilities, such as using an arm ergometer, recumbent bicycle or water exercise. Aim to exercise aerobically 20 to 30 minutes, three days per week, at a moderate-to-somewhat hard intensity.
- Do three, 10- to 15-repetition sets of strength-training exercises for the major muscle groups two times per week.
- Perform stretching exercises daily to improve your range of motion and prevent contractures.
- Start slowly and gradually progress the intensity and duration of your workouts. Take frequent breaks during activity if needed.

### Exercise Cautions

- To help you stick to your program, consider having a trained health professional supervise and monitor your response to exercise for the first two months.
- If you experience spasms during exercise, lower your intensity and increase your recovery periods.
- Progressive sudden fatigue is a sign that you are overdoing it and should reduce the intensity of your workout.

## **SPORTS MEDICINE recommendations for PPS . . . .**

Your exercise program should be designed to maximize the benefits with the fewest risks of aggravating your health or physical condition. Consider contacting a certified health and fitness professional\* who can work with you and your health care provider to establish realistic goals and design a safe and effective program that addresses your specific needs.

For more information, visit [www.exerciseismedicine.org](http://www.exerciseismedicine.org) or e-mail [eim@acsm.org](mailto:eim@acsm.org).

\* If your health care provider has not cleared you for independent physical activity and would like you to be monitored in a hospital setting or a medical fitness facility, you should exercise only under the supervision of a certified professional. The American College of Sports Medicine (ACSM) has two groups of certified fitness professionals that could meet your needs. The ACSM Certified Clinical Exercise Specialist (CES) is certified to support those with heart disease, diabetes and lung disease. The ACSM Registered Clinical Exercise Physiologist (RCEP) is qualified to support patients with a wide range of health challenges. You may locate all ACSM-certified fitness professionals by using the ProFinder at [www.acsm.org](http://www.acsm.org).

Sources: ACSM's Guidelines for Exercise Testing and Prescription and other ACSM publications.

### **MORE ON THIS TOPIC**

Exercise Prescription (Sports Medicine)

Therapeutic Exercise (Physical Medicine and Rehabilitation)

Postpolio Syndrome (Physical Medicine and Rehabilitation)

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## **. . . with those from Post-Polio International**

**Post-Polio Health** (ISSN 1066-5331)

Vol. 19, No. 2, Spring 2003

### **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. (See References.)

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 su-

pervised 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. March of Dimes, 2001.

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## Finding a "polio" PT

Dr. Perlman is excited that the guidelines from the *Sports Medicine* are in line with those from **Post-polio Health**. It is not that long ago when polio survivors, who had been active in sports, were given the very bad advice to drastically increase exercise when they went to sport therapists with new weakness from post-polio syndrome. So, it is remarkable that the American College of Sports Medicine is getting it right. We also know that there is a sizable number of physical therapists in Orange and Los Angeles counties who have been trained in how to create an exercise program for post-polio patients, The easiest to identify are those at UCLA, Rancho Los Amigos, and St. Jude Medical Center. We also know that Western University in Pomona and Chapman College in Orange have trained physical therapy students in post-polio and bracing. There are a large number of polio trained PTs out there, It is up to each of us to find one to help us on an ongoing basis. Dr, Perlman makes it clear that each one of us has to take charge of the direction of our care. If we are on straight Medicare or in a good PPO, we can access polio trained doctors and therapists easily. If we choose a Medicare Advantage HMO or are still in an HMO from employment, the task is much harder. First, we have to educate our primary care physician and probably some of the specialists that he or she sends us to. The best materials are the brochure and booklet from the March of Dimes. Please contact Priscilla Hiers at [prisofoc@aol.com](mailto:prisofoc@aol.com) if you do not have one. We need to get the doctor who we consider to be our polio doctor to prescribe

an exercise program appropriate to type of limitations we have. Next, ask the doctor to help us find a physical therapist who will train and monitor us in conditioning our good muscles without damaging the ones too weak to exercise. Dr. Perlman pointed to research concluding that patients with PPS can increase in strength 1% to 2% per year until they plateau at a level where they are living very well with PPS, whether still walking or in a wheelchair. The key is to successfully manage the worst pain and fatigue, and to consistently do appropriate exercise and other activity. Of course it is very tough to exercise if daytime or night time breathing is difficult. Often a sleep study is helpful. On July 10th Diana Guth will show us how the care and equipment to assist breathing depicted in our 2010 January, March, and May newsletters can help. Please email your questions in advance to [prisofoc@aol.com](mailto:prisofoc@aol.com).

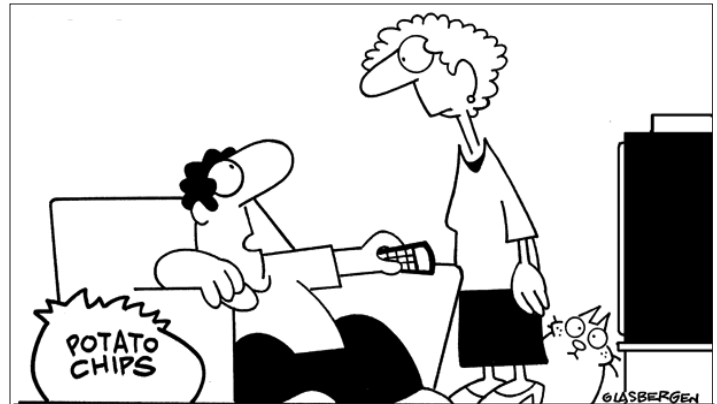
### How to contact Rancho Support Group

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

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

Or email us:

**[Rancho PPSG@hotmail.com](mailto:RanchoPPSG@hotmail.com)**



Dr. Perlman said that I should increase activity. Well, chewing, changing channels, and napping are activities !!!

### How to contact OC Support Group

Call us for information:

Marte Fuller **562-697-0507**

Marilyn Andrews **714-839-3121**

**Newsletter co-editors:**

*Baldwin Keenan* 949-857-8828

[keenanwhelan@cox.net](mailto:keenanwhelan@cox.net)

*Janet Renison* 949-951-8613

[renison@cox.net](mailto:renison@cox.net)

**Agenda ideas for PPSG of OC?**

Please call Aleta at 949-559-7102 or email Priscilla at [prisofoc@aol.com](mailto:prisofoc@aol.com)

VIEW DR. PERLMAN'S MAY 2010 PPS RESEARCH AND CARE SLIDE PRESENTATION AND LINKS TO PHYSICIAN, PHYSICAL THERAPISTS AND MUCH, MUCH MORE:

**Website: [ppsupportoc.org](http://ppsupportoc.org)**

Special thanks to Winifred Hyson, Arlene Trask, Gertrude Mikus. We mention donations but not the amount, as all donations make our support group possible. Please write checks to Polio Survivors Association and write "Orange County" in the memo section. Please mail checks to Priscilla Hiers, Treasurer PPSG of OC, 18552 Cork Street, Fountain Valley, CA, 92708.

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## Rancho Los Amigos Meeting

Saturday July 24th

Documentary Film

# “The Final Inch”

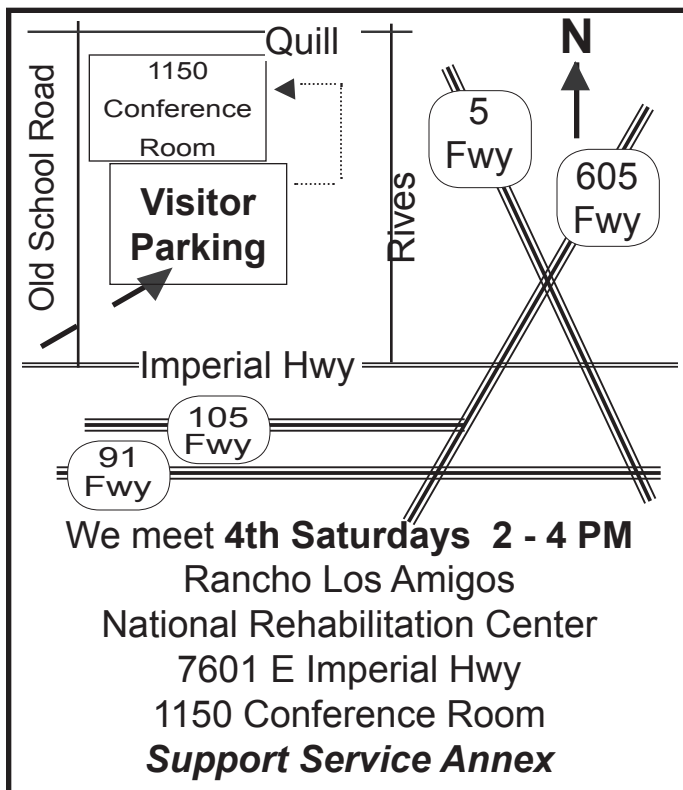
### Future Rancho SG Meetings

Saturday AUGUST 28

&

Saturday SEPTEMBER 25

**TO BE DETERMINED**



### Orange County Meeting

Saturday July 10th

**Diana Guth** BA RRT

Founder Home Respiratory Care  
Los Angeles

Learn the practical use of some of the equipment depicted in our 2010 January, March, and May newsletters

**EMAIL questions in advance to [prisofoc@aol.com](mailto:prisofoc@aol.com)**

### Future PPSG of OC Meeting

TENTATIVE

**August 14th**

*Max Lift Gate and/or Ability Center*

**Chair/Scooter lifts**

for sedans, vans, or SUVs

*Dayle McIntosh Center*

**Accessible low income housing**

