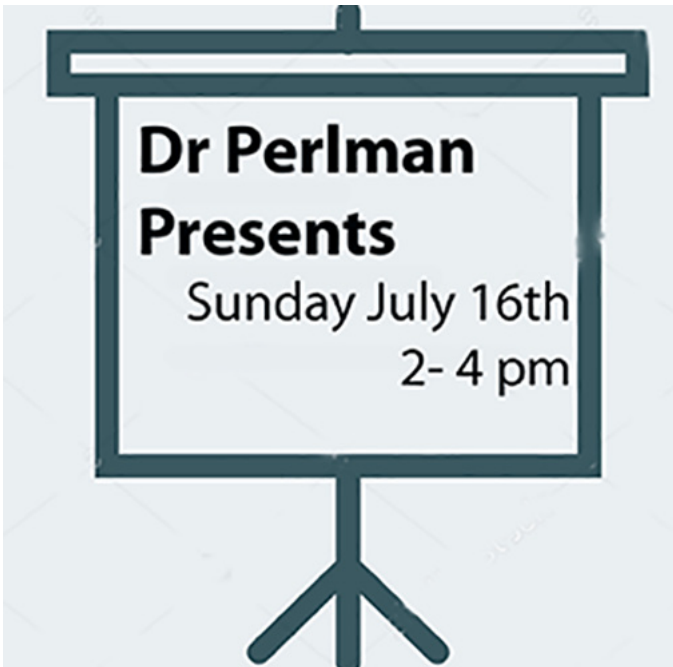


Founded in 1989

The Post-Polio Support Group of Orange County Newsletter

15231 Marne Circle Irvine CA 92604
WEBSITE: ppsupportoc.org

July- September 2017



Dr. Susan Perlman is a prominent neurologist who directs UCLA's PPS Clinic. She also serves as an advisor to Post Polio International, Please come and hear her much appreciated annual **presentation on new PPS research and best care practices for polio survivors.**

September 9th

"Sleep and Respiratory Care"

Diana Guth BA, RRT, a Registered Respiratory Therapist for more than 40 years.

- Do I have sleep apnea **OR** am I hypoventilating when I sleep?
- **Symptoms** of each disorder?
- Is there a relationship between weight gain, exercise, or diet with sleep apnea?
- What is a **sleep study**? What is a **pulmonary function test**?
- What devices are available to help me sleep and breathe?
- Medicare coverage for sleep apnea devices and ventilators?
- **Pain interrupted sleep**?
- Restless Leg Syndrome and Periodic Limb Movement Disorder?
- Can all polio survivors expect to have breathing and/or sleep problems?

Inside this issue

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Excerpts - Julie Simpson's presentation on Physical Therapy May 13th, 2017

Effects of Inactivity

- Deterioration of cardiovascular performance/efficiency
- Metabolic disturbances
- Difficulty maintaining body weight
- Disturbed sympathetic nervous system activity
- Decreased muscle strength and endurance
- Possible emotional disturbances

Continued on Pg. 2

EDITOR'S NOTE:

No polio survivor should use the PARTIAL OUTLINE provided here as an exercise program. Each one of us needs to have an evaluation done by a POLIO TRAINED PHYSICAL THERAPIST. My personal experience with training from Julie Simpson Lori, Morris and Virginia Hazboun at St Jude Center for Rehabilitbeen has been excellent.



Benefits of Exercise

Decreased heart rate and blood pressure
Change in skeletal and cardiac muscles with improved work capacity and efficiency
Increased myocardial vascularity
Decreased blood coagulability
Decrease in fat with increased lean body mass
Increase cellular sensitivity to insulin
Decreased muscle tension
Improved sleep
Increased muscle endurance
Favorable changes in blood lipids and cholesterol
Increased motivation for improving other health habits

Exercise Program Guidelines

- Unique to each individual's needs
- Able to discern between exertional vs. disease-related fatigue
- Should not cause muscle soreness or pain
- Should not lead to fatigue that interferes with daily routine
- Strengthening ex only with muscles at 3 to 3+/5 strength
- Progression of ex is slow
- Determine overuse vs disuse deconditioning
- Pacing should be incorporated into program
- Exercise plan should include rotation of exercise types (stretching, aerobic, strengthening)

- Should be done regularly
- Should be a set program with a time limit & specific exercises
- Exercises should be alternated regularly
- Exercises terminated immediately when experience fatigue (typically described as "twitching" sensation)
- Rest breaks should be interspersed in exercise program

Types of Exercise

Aerobic

Stretching

Strengthening

Aquatic

Aerobic Exercise

Definition: Exercises that stimulate the heart rate and breathing rate to increase for a sustained period of time.

Strengthening Exercise

Research overwhelming supports that muscle needs to be at least 3/5 and "functionally important" to consider for strengthening

Stretching Exercise

- Improves muscle length and joint range of motion for daily activities
- Helps in managing pain, reducing risk of osteoporosis, and reducing risk of falls
- Important to do when muscle weakness present to prevent contractures

Aquatic Exercise

- Recommended in warm pool (88-90 degrees)
- Can use for strengthening, flexibility, and aerobic exercise
- Water buoyancy can be supportive or it can create resistance
- Caution to avoid overuse and fatigue

Benefits

- Decrease pain
- Increase circulation
- Decrease negative effects of gravity
- Improve muscle relaxation Improve endurance
- Reduce edema



Borg Scale - Rate of Perceived Exertion

- 6 .Very Easy
7. Minimal recognition of effort
8. Very light (comfortable walking pace)
9. Can just start to hear your breathin
10. Conversation easy
11. Zero Exertion
- 12. Light exertion – This is where you are developing your aerobic system**
- 13. Somewhat hard**
- 14. You can hear your breathing but you're not struggling**
15. You can talk but not in full sentences – At top end of developing aerobic system
16. Hard work – Just below anaerobic threshold
17. Very hard, Getting uncomfortable and tired
18. Breathing is heavy and you can no longer talk
19. Extremely hard, Body screaming at you to stop
20. Max exertion

Light excercise in the 12-14 range shoud probably be the “stardard”, if there was one, for PPS patients.

Summary of Other Research Findings with Exercise in PPS

- Common Denominator – “Keep activity & exercise with reasonable limits to avoid fatigue or pain”
- Borg scale consistent with EMG recorded level of fatigue
- Perceived decrease in sensation of fatigue correlated with better post-exercise recovery
- Submaximal exercises with rest periods superior to exercises up to sensation of exhaustion

More from EDiTOR on exercise:

I urge all readers to go to a Physical Therapy center **on a par** with the one at St. Jude. Ask for polio trained Pts to design a personalized program for you that you can take to a PT close to where you live. Ask you local PT to communicate with the polio trained PTs when problems arise. And maybe every couple of years go back to the polio trained PTs for re-evaluation.

Permission is hereby granted to:

Polio Support Group of Orange County (CA)

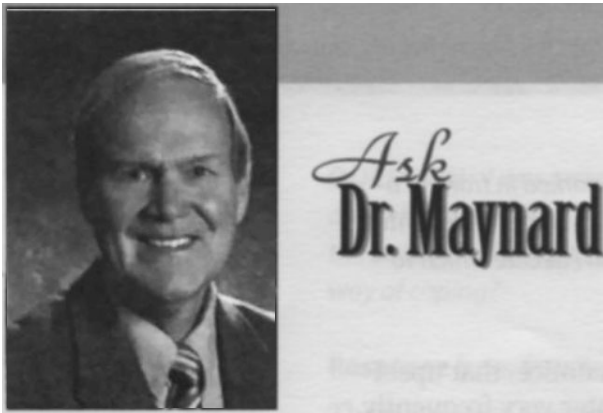
To reprint the following material from Post-Polio Health (formerly called Polio Network News):

Issue: Spring 2017, Vol. 33, No. 2
Article title: “Ask Dr. Maynard”
Author: Frederick M. Maynard, MD
Page (s)/column location: 10

Issue: Winter 2017, Vol. 33, No. 1
Article title: “The Role of the Primary Care Physician in the Life of a Polio Survivor”
Author: William DeMayo, MD
Page (s)/column location: 5,10

Issue: Winter 2017, Vol. 33, No. 1
Article title: “Promoting Positive Solutions”
Author: Stephanie T. Machell, PsyD
Page (s)/column location: 7

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Frederick M. Maynard, MD

Question: I contracted polio at 10 months old in 1953 and it affected my left leg (knee down) and right foot. It's been recommended to me recently to try using an FES Bike with the goal of strengthening my upper leg muscles. Has anyone experienced a gain in muscle strength after using such a machine? I am luckily blessed with almost no pain. My goal is to strengthen my upper leg muscles which are now getting weaker due to post-polio affects.

I have fallen twice in the last two years, when my knees gave out for no apparent reason.

Answer: Please don't become involved with regular use of an FES bicycle. It will not benefit you and may cause you harm. I will try to explain why. And, I will add that anyone recommending FES for a polio survivor with residual weakness and post-polio syndrome does not understand the basis for muscle weakness after a poliovirus infection, let alone what is happening with PPS.

FES (Functional Electric Stimulation) is used to stimulate nerves going to muscles when a person is unable to fire those nerves themselves through voluntary effort or intent. The classic example is after a spinal cord injury when nerve pathways in the spinal cord have been damaged, and therefore, messages from the brain "to move | a leg muscle are blocked from reaching the motor nerve cells in the lower spinal cord that are still alive, and capable of sending a signal to the muscle to contract.

The FES bicycles are a very sophisticated way to electrically stimulate leg muscles in the correct sequences to contract and power the bicycle wheel mechanism. Regular use of this device does strengthen the otherwise weakened and paralyzed leg muscles. What makes this beneficial is primarily the cardiopulmonary conditioning benefits derived from exercising the paralyzed legs.

People with a history of polio have residual weakness after their viral infection due to the death of significant portions of the motor nerve cells that normally innervate and provide the signal to the limb muscles. They have a reduced population of functioning nerve cells and they are usually connected to more muscle cells and tissue than in a non-polio person (3-6 times more). This is largely responsible for the rapid fatiguing of post-polio muscles with repetitive high-resistance work.

If one was to "artificially" stimulate the surviving motor nerves of a polio survivor with a modality such as FES, all of the nerve cells will fire each time the electrical stimulus occurs. They will never get any rest-and-recovery time between repetitions, such as normally occurs with repetitive voluntary effort when groups of nerves fire together and then rest, while their cohort nerves fire in rotating on and off.

There are good reasons to be concerned that repetitive use of FES in polio-involved muscles may become "overworked" and sustain some damage that may hasten further degenerative changes already occurring in PPS muscles (i.e., post-polio weakened muscles that are weak-

ening further due to post-polio syndrome).

I hope that this explanation helps you understand why I made such a strong negative statement about your potential use of an FES bicycle in the opening of this response. To help yourself with weakening of proximal leg muscles, stick with non-fatiguing relatively low repetition and high resistance (for your muscle strength) exercises. Go to www.polioplace.org/living-with-polio and select “exercise in Category. If these do not help enough to prevent falling, then pursue other options such as the use of canes/crutches or bracing. I would recommend a comprehensive post-polio evaluation and view this on Polio Place (www.polioplace.org/post-polio-evaluation). ■



QUESTION: I am in my 80s and have become less and less involved in “changing the world.” I have come to terms with that decision and just want to relax and enjoy life. But at the same time

it seems like everything is so difficult anymore. Errors abound at the pharmacy, at the doctor’s office, the plumber seems not to carry the basic supplies in his truck, the young cleaning lady has a different definition of clean than I have, etc. Do you have advice on how I can just enjoy life?

RESPONSE:

from **Stephanie T. Machell, PsyD:**

It sounds like those you rely on are what’s preventing you from relaxing and enjoying your life. It must be frustrating to have to deal with so many incompetent people, especially when all you want is for things to run smoothly. Unfortunately, there is no shortage of incompetence in every walk of life. And that’s not likely to change, even if you

devote all your time and energy to changing it, because you cannot make the incompetent competent.

There is nothing more frustrating and stressful (or impossible) than trying to change others who have no interest or investment in changing. The best way of reducing your own stress is to stop trying to do this. Instead, fire incompetent service providers and find new ones whose work meets your standards. You have a right to high-quality services and care, and though it may take some initial time and effort, once you have your “dream team” in place life will be much more enjoyable. It might further reduce your stress levels to ask for help from a family member, friend, or even someone from your local senior center or elder service program to deal with certain categories of service providers, and/or to find ones known to work well with older people with disabilities.

If the major stresses you experience come from other people’s behavior and attitudes, it’s worth learning to change the way other people’s behavior affects

you. Think about it: Are those who affect you worth the distress they cause? Do they deserve to ruin your day? Of course they don’t. It’s hard, but you can learn to be less reactive to others. Try imagining a scale. At one end are events that are of no importance and/or have no lasting effect on you or your life. At the far end is the very worst thing that ever happened to you. Placing the person/event you find distressing on this scale can help you (re) gain perspective. You can count to ten, or take a deep breath, or find the humor in the situation. You can even vent your frustration to a friend or your journal, as long as doing this allows you to let the frustration go.

Many people find meditation useful in becoming less reactive and more relaxed. And of

course, it has other health benefits as well. No matter what your belief system is, there is a way of meditating to go along with it.

Feeling dis-empowered and helpless is anything but relaxing. Studies show that those who remain engaged with their communities age best. Maybe you can redefine your idea of a peaceful life to include continuing to work for change. Maybe you could volunteer at the senior center to help others find more competent providers, or with your post-polio support group to develop or disseminate educational material to local physicians or pharmacies. ■

The Role of the Primary Care Physician in the Life of a Polio Survivor

William DeMayo, MD,

Summit Medical Rehabilitation, PC, Johnstown, Pennsylvania



On each of my several trips to Post-Polio Health International conferences, as well as on my recent three-week lecture circuit in Australia, I have been amazed at the number of individuals who see my specific expertise as “the missing piece” in their future health, yet their local therapists and primary care physicians (PCP) seem to be relegated to some distant and less important role.

While I appreciate the importance of specific expertise in this sub-specialty area, I often find myself trying to bring folks back to their local resources. In my opinion, regardless of expertise, it is local therapists and PCPs that can have a much bigger role in long term health.

The most obvious reason to conclude this is that a polio survivor’s health is not solely dictated by their history of polio. They are just as susceptible to the same medical conditions as everyone else. In fact, for some, a relatively sedentary life will make them more susceptible.

The following conditions each have an incidence of at least 10% in those over 65 and ALL ARE ON THE RISE in this age group:

- High Blood Pressure (55%)
- High Cholesterol (45%)
- Diabetes (20%)
- Cancer (> 10)
- Mental Illness (>10%)
- Back Problems (>10%)

Multiple other conditions pose a significant threat of disability as we get older:

- Obesity
- Coronary Disease/ Congestive Heart Failure
- Arthritis
- Bladder and Bowel difficulties
- Infection
- Lung disease
- Kidney disease

Most individuals develop MULTIPLE chronic conditions as they age:

- For 65-75 year olds
- ◆ >20% had a chronic condition

◆ >50 % had two-four chronic conditions
This trend increases after 75 years of age with >20% having more than five chronic conditions.

Primary care physicians are the “go-to person” for nearly all the above conditions yet, somehow, their role seems to be minimized by many polio survivors. ■



Joint Rancho Los Amigos Orange County Meeting

Sunday July 16th
2 pm - 4 pm

Susan Perlman MD
Director UCLA PPS Clinic
New PPS research and best care
practices for polio survivors.

Saturday August 26 2-4 pm
**Prepare for
emergencies!**

Saturday September 23 2-4 pm
Lazy afternoon at
Cafe La Reina

Saturday October 28 2-4 pm
Topic to be determined

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: Rancho@hotmail.com

Orange County Meeting

Sunday July 16th
2 pm - 4 pm

Susan Perlman MD
Director UCLA PPS Clinic

New PPS research and best care
practices for polio survivors.

Saturday September 9th

2-4 PM
“Sleep and Respiratory Care”
Diana Guth, BA, RRT, a Registered
Respiratory Therapist for more than
40 years.

Saturday November 11th

2-4 PM
CHANGES to MEDICARE and
Health Care in general n 2017
Presented by **HICAP**

OC Newsletter editor :

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abaldwinkeen@gmail.com

Agenda ideas for PPSG of OC?

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

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The OC Group meets on odd numbered months. Its newsletter is published more or less quarterly. The Rancho Los Amigo PPS Support Group meets most months and publishes on even months. We share the same mailing list. All donations are shared equally. On occasion the names of donors but not the amount donated will be mentioned.

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