

» Aging With Polio's Late Effects «

Facts:

- Polio is a neurologic illness that lasts a lifetime, a chronic disorder that manifests its late effects throughout the entire body without regard to the type of polio originally diagnosed or the extent of acute polio residual or recovery.
- Worldwide there are 20 million polio survivors, seven percent of the world's population.
- In North America there are an estimated 1.8 million polio survivors, and half are in their forties, fifties and sixties. (Compared to the 2000 U.S. Census, that 1.8 million is more than double the population of the county of San Francisco.)
- As early as 1875 medical literature reported cases of polio's late effects, but medical treatment and proper management of those effects were unknown until the last two decades.
- Medically, the polio survivor's body is 20 years older than its chronological age.
- Polio's late effects occur in 75% of paralytic and 40% of non-paralytic polio survivors about 15-40 years after the poliovirus attack.

Comments:

Dr. Elizabeth Sandel, Medical Director of Kaiser Fdtn. Rehabilitation. Ctr in Vallejo, CA, stated at the 2003 symposium "Aging With A Disability: The Late Effects of Polio" as follows: "All of us Baby Boomers can identify the effects of aging on function, to varying degrees. In the polio survivor group, however, the effects of aging with a disability caused by polio represent a unique interaction of aging and the disease itself. Evidence-based practice guidelines were not a reality in the early days of treatment and rehabilitation of polio survivors. Today, our lack of appreciation of the late effects of polio can lead to mismanagement as well. This conference aims to educate health care professionals - within our health system and beyond."

** 2003 CONFERENCE VIDEOTAPES **

"Aging With A Disability: The Late Effects of Polio" Symposium sponsored by Kaiser

Permanente National CME Program, with Kaiser Vallejo and SFBAPS, on September 19, 2003 at the Marriott Conference Center in Oakland, CA. Videotapes are available for borrowing from SFBAPS (if a member) or from Kaiser (if a member). They can be purchased from Kaiser (you do not need to be a Kaiser member). Log on to www.kpwellness.org or contact Kaiser Permanente MultiMedia Library, 1950 Franklin Street, 3rd Floor, Oakland, CA 94612. (Phone 510-987-1000)

< Postpolio Books >

SFBAPS has available in its library and sells at a discounted price at its meetings the following books:

1. **Managing Post-Polio: A Guide To Living Well With Post-Polio Syndrome.** Edited by Lauro S. Halstead, M.D. (Washington, D.C.: National Rehabilitation Hospital Press, 1998)
2. **Handbook On The Late Effects Of Poliomyelitis, For Physicians And Survivors.** Rev. Ed. By Frederick M. Maynard, M.D. and Joan L. Headley, M.S. (St. Louis, MO: Gazette International Networking Institute "GINI", 1999)
3. **The Polio Paradox, What You Need To Know (Uncovering The Hidden History Of Polio To Understand And Treat "Post-Polio Syndrome" And Chronic Fatigue).** By Richard L. Bruno, H.D., Ph.D. (New York, NY: AOL Time Warner Co., 2002)
4. **Postpolio Syndrome.** By Julie K. Silver, M.D. and Anne C. Gawne, M.D. (Philadelphia: Hanley & Belfus (an affiliate of Elsevier), 2004)

→ History of SFBAPS ←

Formed in 1991, SFBAPS has members throughout the SF Bay area and state of California as well as in other states and abroad. SFBAPS planned and sponsored in 2000 and 2003 national postpolio conferences in the Bay area featuring internationally recognized medical experts on polio and postpolio. We have an impressive polio memorabilia collection that is displayed on special occasions. Working with Rotary International, SFBAPS placed postpolio books in public and health libraries throughout SF Bay area.

We meet and publish a newsletter monthly, January-June and September-November. Meetings (alternating between speaker and caring/sharing meetings) are the 3rd Saturday of those months at Kaiser Permanente's Ensenada Building, Conference Rooms E1-E3, in Martinez, from 10:30 A.M. to 12:30 P.M.. Polios, friends, families and anyone interested in learning more about postpolio are welcome to attend.

Members receive a list of Bay Area postpolio clinics and medical practitioners familiar with post-polio syndrome, and other helpful resources, and access to a lending library of polio material (audio-tapes, videos, books, newsletters, and other polio-related materials).

We are a California public benefit nonprofit 501(c)(3) corporation, federal tax ID No. 68-0253385. Donations SFBAPS are tax deductible. SFBAPS is supported by an annual membership fee of \$15, or whatever you can afford, and donations. No person unable to contribute financially is denied membership.

The Late Effects of Polio*

An Overview

* postpolio sequelae, postpolio progressive muscular atrophy, postpolio muscular dysfunction, and postpolio syndrome

San Francisco Bay Area Polio Survivors

-- "SFBAPS" --

P O Box 272175
Concord, CA 94527-2175

(California public benefit nonprofit corporation)

Phone - (925) 934-6103

E-Mail - SFBAPS@aol.com

Website --

<http://hometown.aol.com/sfbaps>

SFBAPS' mission:

* Promote well-being and improve the quality of life of disabled polio survivors, in order to enable them to lead a life of dignity and independence;

* Educate and communicate to polio survivors and their care providers, the medical community, and the general public accurate information about the late effects of polio and other topics related to its resulting chronic conditions and long-term disability;

* Be a resource center to members and the community for information on issues and needs related to postpolio and the disabled; and

* Associate and cooperate with other organizations and groups advocating for the benefit of all persons with disabilities.

Member of
Post-Polio Health International, Inc. (PHI)
4207 Lindell Blvd., Suite 110
St. Louis, Missouri 63108-2915
(341) 534-0475 [(341) 534-5070 Fax]
E-Mail: info@post-polio.org
Website: www.post-polio.org

» Poliomyelitis (POLIO) Explained «

Acute polio - a viral disease that enters the body through the mouth and resides in the gastrointestinal tract, and in some cases, becomes blood-borne and invades the central nervous system (CNS). The manifestations of the infection can range from an *inapparent infection* to a severe paralytic illness. There are three distinct types of poliovirus, and infection by one type does not confer immunity against infections by the other two types.

Abortive polio - a brief systemic illness often limited to one or more of the following symptoms: sore throat, headache, vomiting, and fever, in which clinical or laboratory signs pointing to CNS involvement fail to develop.

Paralytic polio - a major illness in which severe muscle weakness, or paralysis of *one or more* muscles, develops. Location of paralysis depends on where the virus caused injury or death of motor nerve cells in the spinal cord. (*Spinal polio* affects muscles of legs, arms, and back. Also affected may be muscles of thorax, including intercostals, and diaphragm with its motor nerve cells located just below the brainstem. *Bulbar polio* results from paralysis of muscle groups innervated by cranial nerves, including those of soft palate and pharynx, face, tongue, and paralysis of respiratory center of the brain.)

Nonparalytic polio - an example of major illness with involvement of the CNS, as manifested by spinal-fluid changes or appropriate clinical signs, such as fever, headache, vomiting, neck, back, trunk, or limb pain, and stiffness of neck or back, but in which acute or residual muscle paralysis is *not readily apparent*. **Note:** "New weakness is the cardinal symptom of PPS. The new weakness is located in muscles previously affected by polio as well as in muscles believed to be *unaffected* by the original illness. At first glance, the phenomenon of 'unaffected' muscles becoming weak seems contradictory but, in fact, is well known. Usually, it means that the polio was so mild in those muscles at the time of the original illness that the individual, as well as health care professionals, was unaware of any polio involvement in those particular limbs. However, there was enough loss of motor neurons that after many years of overuse, new weakness developed."

~ CRITERIA FOR DIAGNOSING PPS ~

1. Prior episode of polio with residual motor neuron loss (which can be confirmed through a typical patient history, a neurological exam, and, if needed, an EMG exam)
2. A period of neurologic recovery, followed by an interval (usually at least 15 yrs) of neurologic and functional stability before onset of new problems.
3. Progressive (gradual or abrupt onset) new weakness or abnormal muscle fatigability (decreased endurance or function), with or without generalized (excessive) fatigue, muscle atrophy, or pain (muscle and/or joint)
4. Exclusion of medical, orthopedic, or neurologic conditions that might cause these symptoms.

* COMMON SYMPTOMS OF PPS *

- Unaccustomed fatigue - either rapid muscle tiring or feeling of total body exhaustion.
- New weakness in muscles - both those originally affected and those seemingly unaffected
- Pain in muscles and/or joints.
- Sleeping or breathing difficulties
- Decreased ability to tolerate cold temperatures.
- Functional decline in activities of daily living such as walking, bathing, shopping, hobbies, etc.
- Voice, swallowing, or esophageal difficulties
- Depression/anxiety

PREVENTING OVERUSE IS THE KEY!

'Conserve' to 'Preserve'

Many polio survivors have been pushing beyond the capacity of their polio-damaged muscles. They have been overcompensating, overachieving, and overusing weakened muscles. It is time to look at LIFESTYLE and *think* MODERATION, CONSERVATION, and COMMON SENSE. Failure to do that causes and advances both neuromuscular and musculoskeletal disorders in polios. For good management of PPS, polio experts at national and worldwide polio conferences advise the following:

1. Listen to your body; heed its warnings.
2. Pace yourself. Slow down. Plan ahead.
3. Prioritize activities, commitments and desires. Do only that which your energy and muscles allow without fatigue, pain, spasm or fasciculations.
4. Do not over exercise; *the "no pain, no gain" theory does not apply to polio survivors!*
5. Increase flexibility by *stretching* muscles.
6. Do not overuse; *avoid activities causing fatigue lasting more than ten minutes.*
7. Avoid activities that cause pain.
8. Rest when you are tired; *stop for 15-30 minutes rest when needed, perhaps several times a day and before experiencing fatigue.*
9. Avoid or reverse weight gains. Eat breakfast that includes *protein*. Eat protein 2-3x/day.
10. Do not smoke, drink, or take drugs that *interfere with respiratory function or reduce coordination.*
11. Use medications cautiously and with your physician's knowledge; be aware of medications contraindicated for polios.
12. Exercise caution when taking anesthetics.
13. Carry or wear a "medical alert" identifying breathing and swallowing problems, cold and medication sensitivities, proper body positioning for you, etc.
14. Have the best body positioning and support while awake and asleep.

15. Do not use muscles in one position for long; *change positions often to lessen fatigue and stiffness.*
16. Avoid stress, both *physical and emotional.*
17. Treat respiratory illness early. (Many polios have subclinical pulmonary distress from weak breathing muscles that is often undetected without proper *neuromuscular* pulmonary function tests, sleep studies, blood oxygen tests. Often there is carbon dioxide retention problem and supplemental oxygen may be life-threatening. The distress may cause complications when undergoing surgery or experiencing other illness. Get baseline pulmonary tests and evaluation by a pulmonary physician experienced with treating neuromuscular disease patients.)
18. Make full and regular use of best assistive devices & DME.
19. Educate yourself, your family, and your health professionals about postpolio and your needs.
20. Discuss problems and opportunities with others at postpolio support groups.

Awareness of The Late Effects

Few health professionals understand The Late Effects of Polio. It is **important** that polio survivors have complete general **medical and neuromuscular evaluations by providers knowledgeable about polio and its late effects** to determine if the Late Effects are being experienced and to what extent and proper treatment. SFBAPS has a list of polio experts in the SF Bay area.

Social Security Administration now recognizes polio's late effects as a **disability** and has issued **criteria for evaluating** the ability of polio survivors to obtain or continue employment. See "*Policy Interpretation Ruling SSR 03-1p Titles II & XVI: Development and Evaluation of Disability Claims Involving Postpolio Sequelae*", effective July 2, 2003, SSA's Program Operations Manual System (POMS) regulation DI 24580.010. For new ruling, go to www.post-polio.org/ipn/di245801.html or <http://www.ssa.gov/regulations/articles/ssr-03-1p.htm>

The Golden Rule for PPS

"If anything causes *fatigue, weakness, or pain*, DON'T DO IT!" (or do a lot less of it)

Polio survivors should examine their work and home daily schedules, and **modify, if necessary, the intensity and timing of activities**. *Utilize appropriate energy-saving techniques and equipment.* **Set priorities.** Decide what is truly important. Learn to **PACE** yourself! **Plan** activities ahead and plan time for recovering from them. **Heed** your body's warning signals. **Work smarter, not harder.**

There is no more time to waste!