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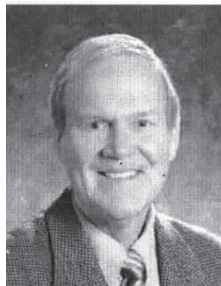
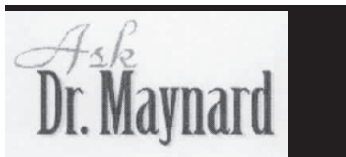
The Post-Polio Support Group of Orange County

NEWSletter

September 2011

15231 Marne Circle
Irvine CA 92604

Website: ppsupportoc.org



Q Often we polio survivors have very few options that are helpful in understanding our circumstances and what direction to take. Thank you for being available to provide this important service. Here is my question in three parts. When I read *The Polio Paradox* by Richard L. Bruno, PhD. he assured us that post-polio syndrome (PPS) is not life threatening. Is this still a valid statement? Is there any evidence to the contrary? Secondly, will the effects intensify and cause weakness to the level that one experienced during acute polio? Also, does PPS affect the brain's ability to function normally in speech, sight or thought processes (through stress or brain lesions)? Mr. Maligia

A There is no evidence that PPS is "directly" life threatening. PPS symptoms can become sufficiently disabling to "indirectly" shorten one's

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editorbaldwin@ppsupportoc.org

life, such as by imposing a fearfully sedentary lifestyle that leads to hypertension, obesity, high cholesterol and heart disease. If severe post-polio breathing and swallowing problems develop and are not treated appropriately, critical life functions can also be put in jeopardy.

A clear answer to your second question is more difficult. Theoretically, at least, one could again become as weak as one was at the time of initial recovery from the acute polio infection. In my clinical experience of 25 years, this never happens. While severe worsening may happen TO a post-polio person, it does not result FROM post-polio syndrome as defined by a consensus statement of medical researchers (March of Dimes Birth Defects Foundation, 1999, Identifying Best Practices in Diagnosis & Care, Warm Springs, GA: March of Dimes International Conference on Post-Polio Syndrome). Certainly PPS will not be more debilitating than acute polio, because it develops slowly and does not suddenly challenge all critical life functions like an acute infection does. Additionally, small changes in motor function can

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and should be treated with appropriate rehabilitative strategies, such as use of compensatory devices and making activity changes.

Last, PPS does not directly affect the brain's capacity to see, talk or think, but it can at times affect those functions temporarily if its symptoms (such as severe fatigue or pain) are so intense that they overwhelm one's concentration and/or alertness. When well rested, all brain functions will return to their normal state.

Editor note: This last paragraph hits home! Although I am much stronger and have much more endurance than when I first had PPS, I have recently had several episodes in which I lost considerable cognitive function. My physical improvement does not immunize me from fatigue! If anything it might induce me to overwork and take on too much stress. Baldwin Keenan

Q *I am 69 and had polio in my right foot when I was 20 months old. I have had tendon transplants, heel cord lengthening surgery, and some toes fused. I wore a short leg brace following surgeries when I was eight years old at Warm Springs in Georgia. I had five children and have always been active, e.g., marched in the band, rode horseback, hiked, skated and swam, and usually did it better and faster than the others. (I was still "different" though.) I have had rheumatoid arthritis since age 30 and now have osteoarthritis. I noticed at age 40 that I was getting much weaker and more unstable on my feet. My right calf is much smaller than my left one. All the tricks I used to hide my limp failed me. Since a total hip replacement. I tire much more easily and walk with a cane. (I have a 1 7/16 inch difference in leg length.) I also go to a pain clinic for spinal stenosis. Should I walk as much as possible (30 minutes or so a day) or "save my strength." and pray tell, save it for what?* Name withheld

A Thank you for sharing your story. It illustrates the challenges faced by people with moderately severe polio-related residual weakness who have led surprisingly active lives. You, as have many others,

faced declining strength already in middle age. You next confronted age-related and, possibly, overuse-related complications, such as hip arthritis. Rheumatoid arthritis and spinal stenosis would be considered unrelated medical conditions (also known as "co-morbid medical conditions") that complicate and compound your post-polio condition. I would advise you stay as active as you can while not aggravating your pain problems. You may wish to consider water exercise workouts to maintain fitness and vitality, rather than walk "as much as possible."

I identify with your rhetorical question of "save my strength, and pray tell, for what?" You should use what strength you still have to fulfill your life's priorities requiring motor function as best you can. You should not obsess about saving your energy for unknown future needs. Please, just don't push yourself to such a degree that you hasten the day when you can't even walk at all or do transfers by yourself. Post-polio life requires constant rebalancing, like walking a tightrope!

Editor note: This last paragraph echoes what Dr. Maynard and the other physicians emphasized at the PHI Conference in Warm Springs that "Conserve to Preserve" is not medically accurate. Rather each of us needs to have a "polio PT" "train us one-on-one with exercises and activities which will maximize our potential for living well with PPS. Baldwin Keenan

Have you donated to the newsletter lately?

Polio Survivors Ask...

Nancy Baldwin Carter, BA, M Ed Psych, Omaha, NE
originally published November 16, 2009

Part I — Opening the Door

The subject doesn't come up much. Not many in the post-polio community seem to want to talk about it.

...Even though the American Medical Association declared it a disease well over forty years ago, in 1966. ...Even though the prestigious medical journal, JAMA, published the results of a two-year study that says it's a "primary, chronic disease with genetic, psychosocial, and environmental factors influencing its development and manifestations."

...Even though this disease is often progressive and fatal. By now you may have guessed—the subject here is ALCOHOLISM.

Sounds serious, doesn't it. Knowing this, would we still rather not talk about it? Would we prefer to pretend there is no problem? Are we so steeped in ancient myths of shame and secrecy that we can't bear the thought of facing the alcoholism reality?

Of course not!

We're talking about it because the U.S. Department of Health and Human Services says that people with disabilities have an even greater likelihood of having alcoholism than the general population's risk of at least 10%—perhaps as much as two to four times greater. That includes us—nearly 800,000 U.S. polio survivors, as many as 20 million worldwide.

We're talking about it because the alcoholics among us are our spouses, our children, our parents, our siblings, others we love—maybe even you and me—all people with a treatable illness who can find help.

Turns out alcoholics aren't necessarily people who end up lying dead drunk in the middle of the street—or bums living under the bridge. Could be they're doctors or carpenters or waitresses or men of the cloth. Some only drink periodically. Others don't drink in public. Alcoholism doesn't seem to care. Alcoholics are unlike in so many ways. But the one thing they all have in common is an obsession for drink that eventually leaves them afflicted in mind, body, and spirit.

Alcoholics, perhaps unaware of all the consequences of excessive drinking, may be ruining more than relationships and self-esteem with their boozing. Alcohol takes a terrible toll on the body. It is, for starters, an irritant and a depressant. The list of medical conditions caused or worsened by alcohol is alarming. How about anemia, cancer, heart problems, diabetes, epilepsy, liver disease, kidney disease, pancreatitis, esophagitis, bleeding disorders—plus a long catalog of others. We're talking major physical illness here.

PHI's Handbook tells us that certain non-alcoholic

polio survivors, who might otherwise drink socially with little problem, should avoid drinking alcohol because of potential problems with swallowing and breathing. Those with post-polio weakness should know that drinking alcohol can impede judgment and coordination, increasing the possibility for accidents.

A lot of denial runs through an untreated alcoholic's head—in fact, denial and its partner, distorted reality, are outstanding symptoms of alcoholism. Such alcoholics find themselves torn apart inside, as A.A.'s basic book, *Alcoholics Anonymous*, puts it, left to face “the hideous Four Horsemen—Terror, Bewilderment, Frustration, Despair.” They may be consumed with feelings of sadness, guilt, and uselessness. Often the disease takes a frightfully hopeless turn.

We're way beyond thinking of alcoholism as a “moral weakness”—we simply don't buy that nonsense anymore. Alcoholism is an incurable disease that can be managed, offering alcoholics who are serious about recovery a life of freedom from alcohol. There is hope. There is a way.

Today over two million recovered alcoholics live productive, fulfilling lives through using the principles of *Alcoholics Anonymous*. They made the decision to seek sobriety on their own and discovered the same path followed successfully by millions of others over the past 75 years.

A.A. is here to help.

MORE ABOUT ALCOHOLICS ANONYMOUS

Interested in knowing if A.A. is for you?

Go to www.aa.org/subpage.cfm?page=12 on the official A. A. website and answer questions that will help you decide. For much more information, go to www.aa.org/ the full AA website. To find an A.A. meeting go to aa.org/lang/en/subpage.cfm?page=28Meeting or turn to *Alcoholics Anonymous* in your local yellow pages.

Nancy Baldwin Carter, B.A., M.Ed.Psych, from Omaha, Nebraska, is a polio survivor, a writer, and is founder and former director of Nebraska Polio Survivors Association. Her article appears courtesy of Post-Polio International.

Sleeping (and Breathing) Better: 30 Years of Progress

Judith R Fischer, MSLS,

IVUN Information Specialist, info@ventusers.org

Thirty years ago, the April 18, 1981, issue of *Lancet*, a renowned British medical journal, contained an article entitled "Reversal of obstructive sleep apnoea by continuous positive airway pressure applied through the nares."¹ Written by lead physician and researcher Colin E. Sullivan with his colleagues in Sydney, Australia, it described the first use of what we now know as continuous positive airway pressure (CPAP) therapy to treat obstructive sleep apnea (OSA) noninvasively. Before CPAP the treatment for OSA was an invasive tracheostomy.

In OSA, people experience a cessation of breathing (apnea) during sleep because the muscles of the throat collapse to block the airway. The CPAP therapy works by forcing a continuous flow of air down the airways to keep them open during sleep to prevent episodes of apnea. The individual wears a nasal, full or partial face mask, or nasal pillows connected by tubing to a CPAP unit.

Beginning in the 1950s, sleep medicine pioneers Nathaniel Kleitman, Elliot Weitzman, William Dement and Christian Guilleminault discovered and identified sleep stages that became the basis for understanding the influence and effects of sleep on breathing in the late 1970s.² (The Association of Sleep Disorders Centers was founded in 1976.)³

Sullivan expanded on those discoveries and characterized the pathophysiology of adult sleep apnea, later studying the use

of noninvasive ventilation during sleep to manage respiratory failure. He helped develop the technology of CPAP and a variety of mask interfaces for ResMed,⁴ established and headquartered in Australia in 1989.

Taking CPAP a step further, Mark Sanders and Nancy Kern published an article in *CHEST*⁵ in 1990 describing the use of noninvasive ventilation at two different levels of pressure: higher for inspiration, lower for expiration. Commercially developed by Respironics,⁶ Inc., in Pittsburgh, Pennsylvania, this method of bilevel positive airway pressure was patented as BiPAP®. Although originally intended for people with OSA, this form of bilevel ventilation became widely used by people who needed nighttime ventilatory assistance. It offered an alternative to the volume and pressure ventilators that have alarms and more safety features for 24-hour use and are more expensive. Many companies in many countries around the world have since developed their own versions of the original devices.⁷ ResMed later developed its own bilevel units.

CPAP and bilevel use has skyrocketed in the past 30 years. CPAP's rise can be attributed to the high incidence of OSA in the general population, estimated at 12 percent. Auto-titrating, or automatic, positive airway pressure (APAP) units have been developed that are more sensitive in adjusting to individual breaths. The use of bilevel units as a first step in treatment that improves sleep and breathing in people with neuromuscular disorders such as ALS, muscular dystrophy and post-polio, and in children with CCHS, has gained widespread acceptance. The availability of bilevel units in developing countries that

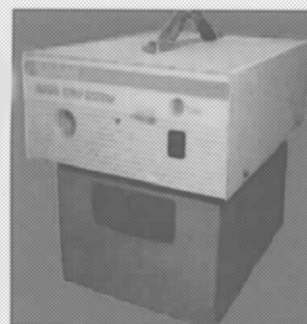
cannot afford volume or pressure control ventilators for home care has also contributed to its increasing use.

It is not an understatement that CPAP and bilevel units have improved the sleep and breathing of countless thousands of people and, in the process, have saved lives.

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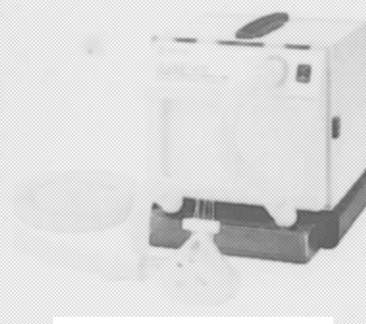
Photos Courtesy of Sam Chang, ResMed



First CPAP 1988-1989
Sullivan Branding



S9 Elite™ CPAP, 2010



BIPAP©ST, 1990



BIPAP©AVAPS™, 2007

Seniors halted Insurance Company take- over of Medicare last Spring

I serve as secretary for Retired Carpenters Club 108. In April, when Congress voted to change Medicare to a voucher system, they were deluged with letters, petitions, and emails from us and thousands of other senior organizations. Congress is now well aware that a solid majority of Republicans, Democrats and unaffiliated voters do not want Insurance Companies controlling Medicare.

Medicare must be reformed, but not by privatizing or vouchers. We worked hard at our jobs expecting Medicare upon retirement. It has worked well. Medicare has an administrative cost of 4%, while private insurance companies administering HMOs an PPOs charge Medicare 20% to 35% overhead and profit. Why jeopardize one Government Program which works well by giving insurance companies total control through a voucher system?

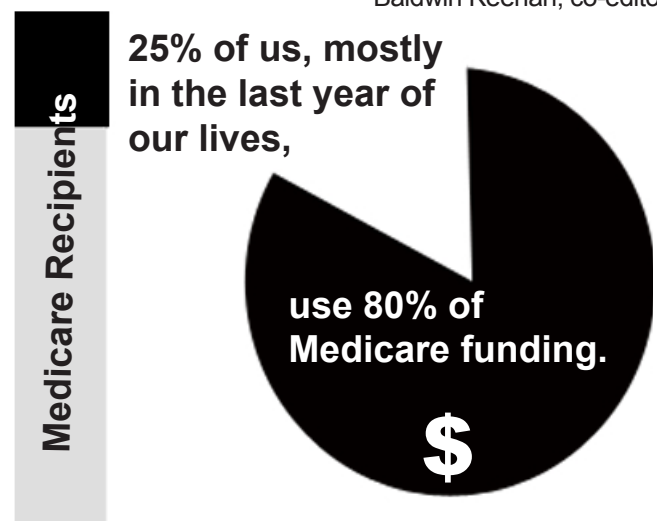
No cuts needed if we report all fraud and stop needless end of life Medicare expenditures !!!

We as recipients have an obligation and the ability to control Medicare costs in at least two critical areas: One is **fraud and abuse** by a few immoral providers and recipients, costing Medicare about 3% of its funding. We cannot sit silent. It is our money being stolen. We have a moral and patriotic duty to turn in the cheaters. Some Durable Medical Equipment (lifts, wheelchairs, ramps, braces etc...) Providers have been investigated and prosecuted recently, as well as some doctors and phoney patients. **Call the Inspector General Hotline: 1-800-447-8477.**

Second, we need to help Medicare spend its funds where they will actually help us be healthy. **25% of us use 80% of**

Medicare dollars, mostly in the last year of our lives and often during pointless hospitalizations. Seniors across the USA have to give clear instructions to the doctors and hospitals as to how many extravagant tests, invasive procedures and surgeries that we want to have preformed when we are the end of our road. Changing the current long-standing pattern of painful, futile and extremely costly expenditures at the end of life **does not require legislation.** Rather we need ongoing discussions held in our living rooms, churches, senior centers, doctors' offices, support groups, and family and community gatherings. The President and Congress must encourage these discussions. Our end-of-life decisions will make or break Medicare. These are very personal, uncomfortable conversations and need to occur and be written down and given to family, doctors and hospitals long before a crisis occurs. If we do not stop wasting healthcare dollars in the last years of our lives, both young and old will be in an endless struggle against wolves in tailored suits who are salivating about dismembering Medicare. We must protect what generations before us fought long and hard to achieve.

Baldwin Keenan, co-editor



The result of families and sometimes patients wanting doctors to “do everything”.

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a service of post-polio international

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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**

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Agenda ideas for PPSG of OC?

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Special thanks to Winfred Hyson, Pauline Bauman, Maurice Goodban, Deni Hunter, Carol Hyington, and Barbara Wood. 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
September 24th**

2pm - 4pm

Gadgets and things to make life easier. Bring any kitchen tools or gadgets, or other things that you use to assist with everyday tasks. Share ideas that work for you. If they work for you, they will probably help another person.

Future Rancho SG Meetings

Saturday October 22nd

TO BE DETERMINED

**Saturday in early December
Rancho Los Amigos Doctors' Report**

Orange County Meeting

Saturday September 10th

Nutrition

Eating well with PPS

2pm - 4pm

See map below

Future PPSG of OC Meetings

Saturday October 8th

Changes in Medicare

Health Insurance Counseling and
Advocacy Program

Saturday November 12th

New reading devices for the disabled

Nancy Stanton of Braille Institute

Saturday in early December

Rancho Los Amigos Doctors' Report

