

# NEWSLETTER

Post-Polio Support Group of Orange County

Founded 1989

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

15231 Marne Circle Irvine CA 92604

January 2017

**Finger Food Potluck and Informal Discussion of “What each of us has found to work and not work in Living with Post-Polio Syndrome.”**

Saturday Jan. 14th 2 - 4 pm

Please verify your email address to [abaldwinkeen@gmail.com](mailto:abaldwinkeen@gmail.com)

**Editor Baldwin Keenan’s Note:** *I hesitated in re-printing this article on weight loss by Sunny Roller. Not all of us have the resources to hire some limited household help and pay for a modest gym membership that she has. We may or may not still be driving. However, we might have accessible kitchens or friends or family to help us prepare healthy meals. Many of us have Medicare Advantage plans that include exercise programs. In Southern California farmers markets abound. And stores like Traders Joe’s offer reasonable prices on quality produce and grains. Even Ralph’s and other chains have radically changed their vegetable and fruit section to include locally grown organics. I have lost 30 pounds and kept it off. Even after I had stopped using a power chair and getting more exercise, it took my cardiologist staring me down to motivate me. He told me that I would die young, if I didn’t change my habits. FEAR was my primary motivator. I find that I need and want to eat vegetables at every meal. Now, I am motivated by renewed mobility from putting less stress on my body and getting a carbon fiber walking brace. I like the way I feel being at my correct weight for my BMI. All of us live with PPS. How well we live with it depends on how we care for our own bodies. Sunny describes her psychological motivation path. Please*

*read what she has to say. She is a long time “polio activist”. If you are not overweight, it may motivate you to stay this way. If you are, her insights may help you to find what will motivate and sustain you to not let weight gain make PPS worse. However we shake it, achieving and maintaining weight loss a **combination** of DIET, APPROPRIATE EXERCISE and PSYCHOLOGICAL MOTIVATION and SUPPORT. **Read on:***

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## Why the weight? Losing a few pounds is possible ... right now. Why wait?

Sunny Roller, Ann Arbor, Michigan

Even if one uses a wheelchair full time and has a metabolism that is a bit slower due to aging, losing weight is possible. I had almost given up, but then 14 months ago, my doctor fiercely demanded that I lose 10 pounds. If I did not, she threatened to infuse me with some creepy medication. How terrifying!

At that time, since I had quit walking with braces and crutches two years before, I was close to 50 pounds overweight. And I knew that the extra weight was not only undesirable; it also made my abilities to transfer and move about so much more strenuous and dangerous. As I pushed, twisted and lifted my body around every day, my hands, arms and shoulders were at imminent risk for injury and worsening carpal tunnel syndrome. back, I started to struggle with overweight issues at the age of 11. As I grew into womanhood with an obvious physical disability and a polio survivor's drive to succeed, losing weight was usually on my mind. It plagued me like a whispering snake, reminding me that I was too fat, which magnified my shame.

I sincerely wanted to shed the pounds, but could never figure out how to do it. Or maybe I wasn't scared enough to do it. My thoughts ranged along a scale from "why this weight?" to "oh, why not wait?" Throughout my busy adult life, I ate when the other girls were out dancing or flirting. I ate at social events with friends. It was easier to meet for dinner than to go roller skating together. I also ate poorly; grabbing fast food when I was super-achieving to meet my latest professional work deadline.

But now, in my retirement years, "why not wait" had abruptly turned into "don't wait; too much weight!" For 58 long years, I had not been caring for my body properly. I didn't know how. My half-hearted attempts had always failed.

Somehow, though, I had actually hung onto hope. A spirited twinkle inside me knew that, "All things are possible." I did believe that for me there had to be a key to success. Other people lose weight, why can't I? I wasn't born overweight nor was I overweight as a little girl with a disability from polio. I wanted to get back to who I really am — innocent and unburdened — free from obesity and that incessant snake murmuring in my ear.

So, optimism in hand, with the ironically "blessed threat" of some freaky new medication propelling me forward, I began arduously searching. My deep inner resolve arose. I hunted for a logical strategy and a little magic to help guide me on a new path to weight loss. One that was feasible and effective. Delightfully, I found both — the strategy and the touch of magic.

The first step was to pay attention to the process of caring for myself. Really taking good care. What a lovely goal. Polio survivors do know how to set a goal and achieve it and I was now adamant. Focus, focus, focus. Then re-focus when focus wanes. The next step was to choose a strategy that involved a comprehensive set of tactics. I needed to go at it from all angles — exercise, healthful eating and cognitive/emotional support.

The exercise opportunity already existed. I just had to tweak it a little. I had found a gym program at our local rehabilitation center that would help me. After a time of physical therapy for an arm injury a year before, I attended what was called a "post-rehabilitation gym clinic." For a monthly fee, former patients could work out at the gym with the assistance and support of enthusiastic rehabilitation technicians. I could go every day of the week and work out on the NuStep machine or stand and walk at the parallel bars. They also would help me weigh myself to track weight loss.

Here's where the magic of kindness appeared first. When they found out I was working to lose weight, they lifted their established rule of short-term membership. They agreed to let me work out for as many months as I wished; knowing that my goal had moved from rehabilitation to weight loss.

So, I keep working out at the gym. (For more details on the reasonable high intensity interval training that my post-polio specialist, Frederick M. Maynard, MD. recommended, refer to [www.sunnyrollerblog.com](http://www.sunnyrollerblog.com) and search for the post of May 15, 2015 titled “Recipes for Regeneration.”)

The second part of my strategy was to eat properly. This was a huge challenge because my kitchen is not very accessible and I don't like to cook. But I knew I needed to start eating clean. Eating clean is the latest buzzword young people use to mean “include whole foods like vegetables, fruits and whole grains, plus healthy proteins and fats; and exclude refined sugar and processed food.”

I had been to WeightWatchers numerous times throughout my life and knew they had the most widely acclaimed sensible eating program. So for \$20.00 per month, I signed up this time for WeightWatchers Online. It was convenient and I found a huge selection of recipes that were “clean!”

Not liking to cook was a problem. One day a friend was listening to me trying to solve the challenge of not cooking, when she suggested that I ask my current housekeeper, whose contract was only for cleaning, to prepare three WeightWatcher meals for me each week. Here's where the magic of kindness appeared once more. My housekeeper agreed to stretch her skills. She genuinely wanted to help and encourage me in my weight loss effort. The magic of her generosity and kindness made this part of the strategy work. And my world of “clean eating” joyfully became a reality. I choose the recipes, shop for the food and she cooks them up in my inaccessible kitchen.

I had found a way to exercise and eat healthful foods, but I knew I needed a third tactic — the psychological support to keep going and learn about my weight problem in greater depth. I asked my physician for a referral to a program at the University of Michigan called “The Hunger Within.” She said, “Oh, you don't need that, but if you want to, I will.”

With resolve and referral in hand, I joined the 12-week support/counseling group. It involved a therapeutic technique called cognitive restructuring, which refers to any method that helps people think differently about a situation, event, thought or belief. Cognitive restructuring shifts a person from irrational destructive thought to positive and healthy thinking about any given idea. For class members, it was all about how we see food and the meaning of food in our lives.

When are we REALLY hungry, versus when do we simply WANT FOOD? We learned that with practice, we could change our thoughts about food.

I discovered that I often automatically eat when I am bored or lonely. That kind of emotional eating alone can lead to unwanted obesity. Did you know that some people want to eat a lot of bread because it brings them closer to an important person in their past lives — like a mother or grandmother, whose homemade bread was irresistible and symbolized love and nurturing? Or that some people crave a lot of sugary products because there has not been enough sweetness in their lives; but perhaps abuse or harshness from those around them?

So I have learned that I can change my distorted thinking and practice more constructive ways to alleviate boredom or loneliness as I develop exciting new interests, and build deeper and more active friendships.

The magic of kindness also emerged from the class in a powerfully different way, as I continued my weight loss journey. “The Hunger Within” ultimately teaches that we must practice being kind to ourselves. If we want to become physically healthier, it’s our job to replace any self-criticism with self-compassion. As we forgive our mistakes, and nurture the inner joy and goodness that shone in our faces as little children, our thoughts about other people become kinder and more compassionate, too.

This class is only conducted at the University of Michigan, but Marilyn Migliore, the workshop’s creator and leader for 20 years, relays that there is a website ([www.autochair.com](http://www.autochair.com)) associated with it. This site describes the program in detail and provides an opportunity to purchase the book. She reports that many people across the country have formed monthly reading/discussion groups with weight loss in mind. They study the book, chapter by chapter and apply its premises.

Before my physician’s warning, I had nearly given up. Then I changed my mind. With fierce focus and fresh hope, I worked to adapt that three-part strategy to my unique situation. The kindness demonstrated by those around me has added the magical power that completes the equation. As others continue to teach me how to be kinder and more nurturing of myself, I believe the adipose tissue will continue to fade away. Funny how that works.

Since my physician’s warning in May of 2015, I have lost 15.5 pounds. Not dramatic. Not perfect. But moving in the right direction — about a pound a month. I slowed down during the cold, winter months, but continued to lose a little. Now I am focused on shedding ten more pounds by Thanksgiving.

Losing weight is a feasible goal, even if one is a polio survivor in later life who uses a wheelchair full time. Why the weight? Who needs it? Why wait? From this experience, I can earnestly say — losing a few pounds is possible ... right now. ■

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Issue: Summer 2016, Vol. 32, No. 3

Article title: “Why the weight? Losing a few pounds is possible ... right now. Why wait?”

Author: Sunny Roller

## **Is the Post-Polio Syndrome Associated with Chronic Poliovirus Infection?**

Angelo Genoni, PhD, Konstantin Chumakov, PhD, Antonio Toniolo, MD, University of Insubria, Varese, Italy and Food and Drug Administration, Silver Spring, Maryland, USA

The central message of our study is that post-polio syndrome might be associated with a chronic low-level poliovirus infection caused by the virus type that - at the time of the initial event - had infected each patient. That is, the possibility exists that poliovirus remains in a “quiescent state” in the body for a long period of time.

The conclusion is derived from the study of a cohort of Italian PPS patients (112) and their

family members (51), together with non-polio controls (71), and aged polio survivors with “stable polio” (18). Nearly three quarters of PPS patients appear to harbor “poliovirus remnants” (in other words polioviral genomes and low-level virus activity), while survivors with stable polio very rarely harbor poliovirus.

The identity of the poliovirus remnants is being clarified by genome sequencing using novel techniques in collaboration with Konstantin Chumakov, one of the best poliovirus experts of the U.S. Food and Drug Administration. It is believed, but not completely proven yet, that the poliovirus forms persisting in polio survivors represent “mutated” (that is, genetically changed) derivatives of the virulent polioviruses that were infecting the patients at the time of the acute polio.

It is thought that slow virus infection of the nervous and muscular cells may be responsible for the slowly progressive loss of neural and muscular cells and chronic inflammation. A further conclusion of the study is that poliovirus remnants are not transmitted from PPS patients to their family members. Thus, these poliovirus remnants are not dangerous to the population, nor represent a possible form of reinfection for poliomyelitis.

Finally, the possible infectious etiology (manner of causation-*editor note*) of PPS calls for an “effective cure and prevention.” So far, in fact, anti-inflammatory drugs and other treatments have failed in this field. A possible remedy is seen in the administration of intravenous human immunoglobulins (i.e., antibodies derived from blood donors; a form of “passive” immunotherapy). These antibody preparations also contain anti-poliovirus antibodies.

Our work brings the attention of clinicians and the pharmaceutical industry to the need of antiviral agents for treating PPS. New antiviral compounds are being developed for picomaviruses (the virus family that comprises polioviruses), some of them having activity against polioviruses. These novel antivirals might be tested in PPS patients, provided that the pharmaceutical industry is willing to design and finance clinical trials.

Quantitative methods for evaluating the possible efficacy of these drugs are already available at a number of clinical centers worldwide. Investigations in this field could lead to significant progress as seen over the last few years in the successful therapy of cases with chronic liver infection due to hepatitis C virus. ■

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Article title: Is the Post-Polio Syndrome Associated with Chronic Poliovirus Infection?”

Fall 2016, Vol. 32, No. 4, Page 1

Authors: Angelo Genoni, PhD, Konstantin Chumakov, PhD, Antonio Toniolo, MD, University of Insubria, Varese, Italy and Food and Drug Administration, Silver Spring, Maryland, USA

This study, "Poliovirus Genome in Patients with Post-Polio Syndrome," was funded by The Research Fund of Post-Polio Health International. Toniolo and his team also received PHI funds for the initial work on the project in 2009.

**For more information:** Mid-Study Report: **Summary of Poliovirus Genome in Patients with Post-Polio Syndrome.** *Post-Polio Health*, Volume 31, Number 3, Summer 2015 (<http://www.post-polio.org/edu/pphnews/PPH31-3sum15p6-7.pdf>). Baj A. Colombo M, Headley J, McFarlane J, Liethof M-a, Toniolo A. Post-poliomyelitis syndrome as a possible viral disease. *Int J Infect Dis.* 2015;35:107-116. (<https://www.ncbi.nlm.nih.gov/pubmed/25939306>).

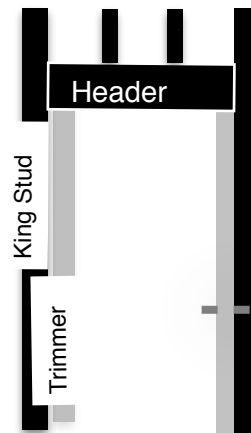
## 4 ways to widen a Door opening

### Swing Away Hinge



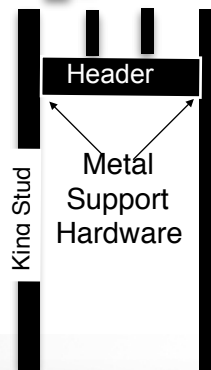
- No drywall removal and may provide 1 1/2" wider opening
- Easy to install, but these hinges can put stress on door frame. Use long screws
- Can be used in conjunction with **Method 1 and 2** below

### Install a wider door Method 1



- Tear out a lot of drywall
- Install new longer header
- Re-install king stud and trimmer
- Install new jamb molding
- Install new wider door
- Increase width **several inches** depending on the size of the new header and door

### Install a wider door Method 2



- Take off very little drywall
- Remove Trimmer
- Install metal hardware to support Header
- Install new jamb molding
- Install new wider door
- New Door could be 2 to 4 inches wider

### "BARN DOOR"



"Modern Look"

- Use **Method 2** to remove trimmers
- Install new jamb molding or drywall the opening
- Opening 4" wider and **more turning space**
- Door shown is for a bathroom, however they come in common "six panel" and many other contemporary styles

Our 2016 July meeting was conducted by Baldwin Keenan and Ed Ripley. Baldwin is active in the Carpenters Retiree Club which has done many projects for the disabled who live social security check to social security check. Ed has done extensive ADA work. They both agree that the BARN DOOR solution is the best because you get the widest possible opening with the "most turning space" and minimal structural alteration.



## Rancho Los Amigos Meeting

Saturday Jan. 28th  
2 - 4 pm

### **Disaster Preparedness**

• Saturday February 25th  
**Annual Anniversary Potluck**

2 - 4 pm

• Saturday March 25th

2 - 4 pm

Topic to be determined 28th

**NOTE** Day of week

We survive on year round **donations** from our readers. Small donations from all readers will ensure that our newsletters and meetings will continue to provide accurate information for polio survivors. Please mail your donation to Polio Survivor Association Support Groups' Newsletters at 12720 La Reina Avenue, Downey, CA 90242. Make your check out to **PSA—Support Groups**, and write "Newsletters" in the memo area.

The Rancho Los Amigos Post-Polio Support Group publishes in even months and the Post-Polio Support Group of Orange County **will now publish quarterly**. We share the same mailing list, and all donations are shared equally. We mention donations but not the amount, as **all** donations make our support groups possible.

## Orange County Meeting

• Saturday Jan. 14th 2 - 4pm

**Finger Food Potluck and discussion of "what works and does not work" living with PPS**

## Future PPSG of OC Meetings

• Saturday March 11th 2 - 4 pm

**Mobility Center** Presentation on personal assistive devices and wheelchair lifts for vehicles.

• **SUNDAY MAY 20th 2 - 4 PM**

**Dr. Perlman** (UCLA PPS Clinic)  
Update on PPS research

## How to contact support groups

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**

Contact PPSG of OC for information:

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**Agenda ideas for PPSG of OC?**

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Priscilla at [prisofoc@aol.com](mailto:prisofoc@aol.com)

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Post-Polio Support Group**

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**FREE POSTAGE FOR  
THE BLIND AND  
PHYSICALLY DISABLED**

