Rancho Los Amigos Post-Polio Support Group

Newsletter - August 2012

Research, Network, and Share – PPS Breathing Disorders

By Janet Whitworth

I have watched three series of Salk Symposium videos on sleep disorders from 2009, 2010, and 2011. The first time I felt a bit scared. They were talking about PPS and other serious breathing disorders. I felt it was being presented to other medical people and some of it a little above my understanding. It was hard to listen to some of it because some of it was about ***me*** and perhaps I didn't want to look into the possible future. As a child I was in an iron lung. Even though it was good information, I didn't want to dwell on it.

The following year I watched the new videos. They were even more interesting and I absorbed more because I had already e-mailed back and forth with Gladys Swensrud. She explained some acronyms and things that I did not understand. After this I started referring to my condition as *neuromuscular* and my pulmonary doctor agreed to switch me from the BiPAP to a Resperonics machine with a backup feature after he graciously consulted with Dr. Benditt, one of the Salk presenters whom he already knew.

My pulmonary doctor is one of the nicest doctors I've ever had, but I think I am a bit of an enigma to him. He diagnosed me with respiratory failure because of my poor lung function and my low oxygen level, but supplemental oxygen did not seem to help me.

Although it was reassuring to have the feature that will spontaneously trigger a breath if the sleeping patient does not, to be honest I did not notice any change. As I did not feel better I kept going to Apria to ask for the machine to be checked. I was getting more tired and in my

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head I was sure it was the machine - not me. They were very helpful giving me a loner while they checked the machine, eventually switching me to a ResMed VPAP ST. In the meantime I was networking with other polio survivors and learning more from my own research. It was really quite exciting!

I wanted to get my doctor to agree to some treatment changes. But it is very hard to get an appointment with him because he is part-time, so I decided to build my case. From what I learned from some other polio survivors I really respect, and reading stuff on the web, I didn't want to wait for my doctor's approval. I felt I needed to prove something first to me, and then to him.

First I gradually weaned myself of the supplemental oxygen. I had already purchased a small finger oximetry monitor from Amazon.com so could check my 02 level any time I was awake. With or without oxygen the reading was hardly different. Next with guidance from my new special PPS friend Rick I changed my bi level settings to lower the EPAP (expiratory positive airway pressure) and gradually increase the IPAP (inspiratory positive airway pressure). I tinkered with the other settings as well. Changing them slowly over days and weeks to what seemed the most comfortable.

What I noticed first was a feeling of more energy and the ability to enjoy a little more activity. And I felt pure joy about not having to carry my little oxygen canister around and have prongs in my nose anymore. Without seeing me, my doctor did prescribe an overnight oximetry test which showed I had just adequate oxygen level for most of the night. By the time I saw him at my long awaited appointment he could see right away I looked better. He authorized Apria to take away the oxygen generator I affectionately named *the screamer* because of the horrible alarm noise it makes when you turn it on.

I have no medical credentials at all, but I believe I was previously holding on to my carbon dioxide because my lungs were not being properly ventilated. I was hypo ventilating, breathing so shallow I practically stopped breathing for some periods of time. When a person receives supplemental oxygen it suppresses their natural incentive to adequately exchange air. People with asthma or other lung disease can benefit greatly from supplemental oxygen, but people with weak breathing muscles can get their own oxygen from the air if they have good ventilation support. Also, the weak breathing muscles make it hard for a person to exhale against air pressure so a lower EPAP pressure can help them expel the C02. It is important to have adequate difference between the IPAP (inhale pressure) and EPAP (exhale pressure) settings.

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After viewing the third series of Salk videos I decided to try using a *Liberty* mask. Two things I like about it are: no pressure mark on my nose that I often get from the full-face mask and secondly I can put my glasses on if I want to see something while I am in bed. But I seem to have allergies or a head cold at present so the nose pillows bothered me and I went back to my old mask after just two nights with Liberty. I will try it again later.

When I went to my last doctor appointment his nurse said it must have been pretty scary for you to be in an iron lung. I said "No, it really wasn't, because back when I was seven years old I was young and dumb." I had never heard of polio. For me it felt like a very bad flu with a high fever. I was struggling to breathe, so after the initial examination when they placed me in the iron lung it was such a relief to be able to relax and let the machine take over the breathing. I was accepting of having my body in a box and just my head outside resting on a pillow.

Fortunately, the iron lung helped me recover and I was soon weaned off and able to breathe unassisted. Of course there is a lot more to my personal polio story but this is just focused on breathing.

I am sincerely grateful to the Salk Institute for organizing the breathing symposiums and hope they will continue in the future. I also think it is important for polio survivors to do their own research, to network and share what they learn. Doctors are great but they can't know everything about us. It is important for each of us to manage our own condition. Before PPS I didn't really know many other polio survivors, and then I didn't really know many with breathing issues like mine. Now I have learned so much from my PPS friends at Polio Outreach of Washington, in Renton, Washington, and more specifically about breathing issues via Hilary Boone in the UK, to Gladys Swensrud at the Salk Institute, and Rick VanDerLinden in Southern California. I am very thankful to everyone.

Janet Whitworth janhat55@comcast.net
Originally published in the PPS Manager, www.ppsmanager.com

We are grateful to Janet Whitworth and Rick VanDerLinden for allowing us to reprint this informative article.

NOTE: Several articles about breathing issues have appeared in the Rancho Los Amigos Post-Polio Support Group newsletter. If you have Internet access, they can be viewed at our website: http://www.ranchoppsg.com Click on the "Newsletters" tab.

Newsletter Update

In 2008, the Rancho Los Amigos Post-Polio Support Group and the Post-Polio Support Group of Orange County decided to reduce newsletter production from monthly to alternate months in order to help conserve the energy of each newsletter team member. The benefit for our readers continues as they will still receive a post-polio support group newsletter every month, either the print or email edition.

Printing, folding, stuffing envelopes, and addressing has always been the most tedious and tiring aspects of newsletter production. We are always preaching to our readers, “Don’t overdo. Conserve your strength for things that are most important to you.” As we age, and the late effects of polio impact our bodies, it is imperative we heed our own advice … “Don’t overdo!”

We’ve decided to heed our own advice. Beginning with this issue of our newsletter, we are taking another labor saving step. The Post-Polio Support Group of Orange County and the Rancho Los Amigos Post-Polio Support Group have jointly contracted with Apollo Printing and Graphics, of Anaheim, CA to print, address, and mail our newsletters.

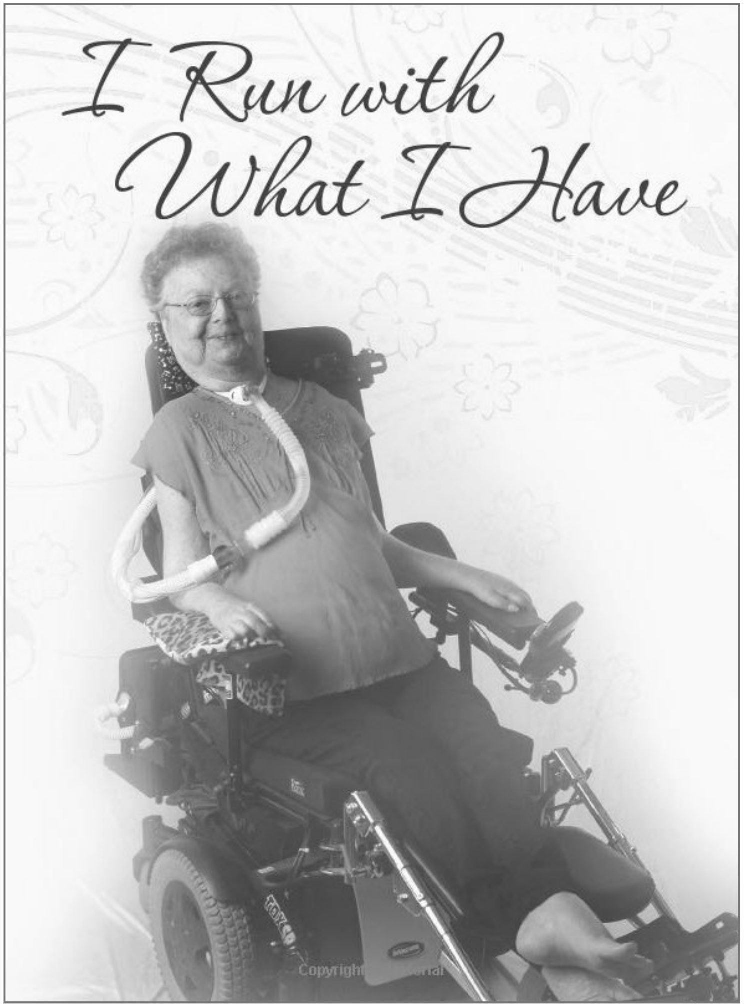
We greatly appreciate your financial support during our recent joint fund raising effort. Those donations were evenly divided between our two groups so each group now has a limited cash reserve. Of course, our contracts with Apollo Printing and Graphics will greatly increase our expenses. So we ask that any future donations be written to the Polio Survivors Association at the address below. Donations to the Polio Survivors Association are tax deductible. As before, all donations will be divided equally between each support group.

Each newsletter editor maintains a combined newsletter mailing list that is updated promptly and submitted each month to the printer. We encourage readers to accept an email version of the newsletters when possible, thus further reducing production cost.

We appreciate comments from our readers at RanchoPPSG@hotmail.com or
postal mail to:

Polio Survivors Association
12720 La Reina Avenue
Downey CA 90242

Richard Daggett, Editor
Rancho Los Amigos Post-Polio Support Group Newsletter



A New Autobiography

by Polio Survivor Bonnie Hagy

Can I run? A woman paralyzed ? Imagine what you might feel when discovering why you are in that chair. This story will invite you to look at yourself with confidence and hope. You might even learn that nothing is impossible.

Life was exciting and beautiful, and nothing seemed to stop Bonnie from experiencing it until she encountered something beyond her control; something she didn't expect. It took many years for her to grapple with herself and to understand why she was on this earth and what her purpose was.

All of us are here for a reason, and maybe this true story will help you discover your unique reason.

About the Author Bonnie and her mother both had polio, and both were in iron lungs. Now living in a small city in the San Gabriel Valley, in Southern California, Bonnie is still experiencing a full life. Although having to use a ventilator 24/7 and traveling around via a power chair, which she operates with her left foot, she goes everywhere with her caregivers and friends. The beach, parks, and malls see her often. But her love for her church tops the week. “I cannot live in this world and confront problems without an ongoing relationship with Jesus,” says Bonnie. “He gives me strength, and learning about how much He loves me keeps me going in the right direction.” Bonnie recently discovered she has breast cancer and is being followed by the City of Hope, which is practically in her backyard.

We are sure you will find this an uplifting personal story. The price is $15.00 You can order a copy through the Polio Survivors Association.

Polio Survivors Association
12720 La Reina Avenue
Downey, CA 90242
USA

info@polioassociation.org - www.polioassociation.org

How Familiar Is This Song … The Original? Polio Lyrics?

“Music! Music! Music!" is a popular song written by Stephen Weiss and Bernie Baum and published in 1949. Teresa Brewer recorded this in 1950. It went to the top of the music charts. You can see Teresa Brewer singing this song on YouTube.

In 2008, author Susan Richards Shreve published her polio story “Warm Springs: Traces of a Childhood at FDR’s Polio Haven” and included this “fight song” of Warm Springs - the polio lyrics they sang while rehabilitating there.

Original Lyrics	**Polio Lyrics**
Put another nickel in In the nickelodeon All I want is having you And music, music, music	Put another muscle in Where the quadriceps have been Cause we know we’ll never win With traces, traces, traces.
I'd do anything for you Anything you'd want me to All I want is kissin' you And music, music, music	What’s the use of stretch and strain What’s the good of pull and pain When our muscle tests remain Just traces, traces, traces.
Closer, my dear, come closer The nicest part of any melody Is when you're dancing close to me	They push our torso, and make it more so When we try to make a muscle go It’s substitution, No, no, no.
So, put another nickel in In the nickelodeon All I want is lovin' you And music, music, music	So even though our hopes have soared Higher than our muscles scored Just the same we thank the Lord For traces, traces, traces.

Two medical students were talking in 1995:

Student number one, *“Did you hear that Jonas Salk died?”*

Student number two, *“Who was Jonas Salk?*

Student number one, *“He introduced the first polio vaccine in 1955.”*

Student number two, *“What’s polio?”*

Meeting Notices

Post-Polio Support Group of Orange County

No OC meeting in August

Saturday, **September 8, 2012** - 2 p.m. to 4 p.m. HICAP on Medicare changes in 2013.

Contact: Marte at 562-697-0507 or Marilyn at 714-839-3121

Website: **www.ppsupportoc.org**

Rancho Los Amigos Post-Polio Support Group

Saturday, **August 25, 2012** - 2 p.m. to 4 p.m. What Works for You: Regarding pain, rest, etc.?

Saturday, **September 22, 2012** - 2 p.m. to 4 p.m. Help! I can't get up: How do we deal with emergencies?

Contact: Diane at 562-861-8128 or Richard at 562-862-4508

E-mail: RanchoPPSG@hotmail.com

Website: **www.ranchoppsg.com**

All post-polio support group meetings are open to family and friends and we encourage their attendance. Post-polio affects you, of course, but it can also affect those around you. Please invite them to our meetings.

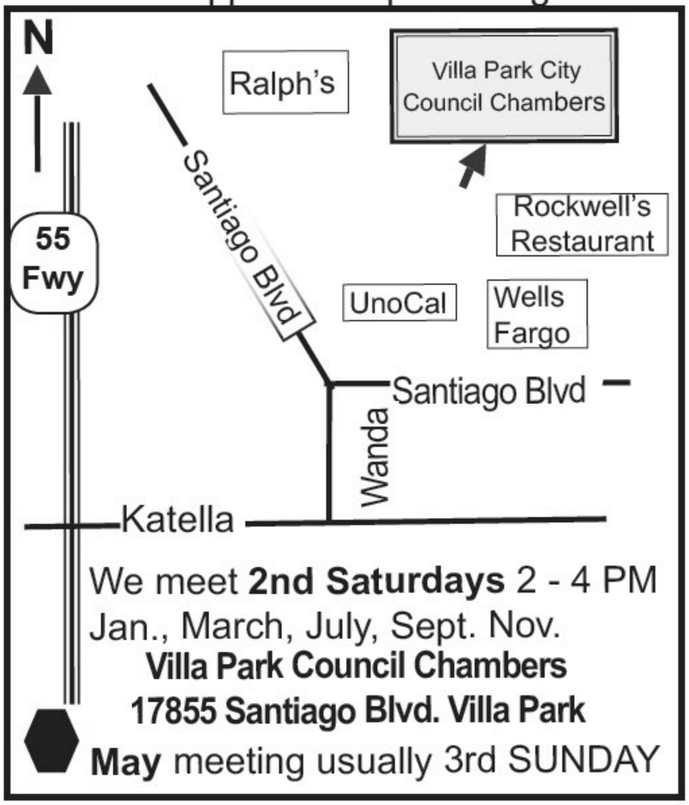
Rancho Los Amigos PPSG
12720 La Reina Avenue
Downey, California 90242
USA

FREE MATTER FOR THE BLIND OR DISABLED

Rancho Los Amigos
Support Group Meetings

We meet **4th Saturdays 2 - 4 PM**
Rancho Los Amigos
National Rehabilitation Center
7601 E Imperial Hwy
1150 Conference Room
Support Service Annex

Orange County
Support Group Meetings



We meet **2nd Saturdays** 2 - 4 PM
Jan., March, July, Sept. Nov.
Villa Park Council Chambers
17855 Santiago Blvd. Villa Park
May meeting usually 3rd SUNDAY