

The Southern California

January

PPS MANAGER

2007

Dedicated to being our best with Post-Polio Syndrome

FROM THE EDITOR

Hi Fellow PPS Managers.

The new year is under way. It seemed like a good time to send a personal message to my fellow PPS Managers. So I did. And it was easy. All I did was return the same message you've been sending me.

The big news is that Rick K. and Gladys finally won their battle with the San Diego Zoo. We've been keeping it low key until the verdict came in, but it's here and we're happy.

Another timely bit of information you'll find in this issue involves Medicare Direct payment for bilevel S/T machines. March 2007 is the breaking point for the new ruling. Will it affect you?

I got a cold and it almost turned into pneumonia – again. So, just to make sure I stay on my toes, I wrote about it.

Finally, the central agency for Post Polio information, Polio Health International, announced an interesting grant. It could result in a method of diagnosing PPS. We'll see.

Have fun....Rick VDL

--○○○○○○○○--

IN THIS ISSUE:

New Year Message from Rick VDL

San Diego Zoo Press Release

How to Get Pneumonia by Rick VDL

Press Release: PHI PPS Study Grant

Letters and much more...



Rick Van Der Linden

Photo by Sandy Van Der Linden

Editor's New Year Message: Keep Up the Good Work!

At the end of every newsletter I thank you for reading the PPS Manager Newsletter. Even though I typed these words years ago and just copy them from one issue to the next, I don't take those words for granted. You, as a reader, give me the opportunity to help someone. I don't know if I would work this hard to help only myself. You give me that extra incentive by allowing me to share the things I learn and maybe help someone else have a better life, too. That's the number one reason I keep doing the newsletter.

And, I thank each person who helped with that particular issue. My wife, Sandy, who staples and attaches mailing labels to 620 newsletters, John at Hemet Printing who goes out of his way to give me the best price and quality he can, my sister Annie who helps me with the graphic layout, and each person who contributed money to keep it going. (That's another reason I keep doing the newsletter: I have to spend the money you guys keep sending me.) And, of course, I thank those who contribute their written work – except when I forget to do so. For the times I've forgotten: Thanks Gladys.

In letters and e-mails, many of you tell me what a good job I'm doing and how much you appreciate the hard work. I have to admit, it's not easy to set aside the many hours it takes to write my little contributions, collect information, assemble the newsletter, convert it for the Internet, get it to the printer, and finally to the post office. But, there is one recurring phrase in the letters you send: Keep up the good work.

Those five words mean a lot to me as a PPS Manager and I'll tell you why. When I decided to find a way to live with this thing, and do it the best I could, I discovered that there are perhaps hundreds of little things that help, and every time I found one, I would think, "Okay, that's a little better. Good. Now what?" Every little step encouraged me.

Okay, since this is a New Year message, it wouldn't be complete without something about making a New Year resolution, would it? We know that a resolution is a firm decision to do or not do something – like making a promise to yourself that you will or won't do this or that. (We won't get into the part where you forget about it two days later.) But, did you know that, in music, a resolution is defined as the movement from discord to concord by changing harmony? In other words, going from disharmony to harmony. Funny how that works. If you do it right, you can kill two birds with one stone. The right resolution can create harmony in your life.

This brings me to a moment in my life about three or four years ago when I made a resolution. I didn't think of it as that at the time – it was more like a shift in attitude. I'd been finding a lot of little fixes to my PPS problems – rest more, bravely use assistive devices, collect Social Security, etc. – but one day it occurred to me that there could be more. I thought: *I'm drowning. If someone threw me a life saver, would I recognize it? And, if I did, would I*

reach out for it? I decided I would. Six months later I discovered the benefits of a breathing assistance machine and, in time, my PPS clock turned back fifteen years.

Looking back, it wasn't really the machine that made the difference; it was my resolve. If I hadn't fought to get the machine, and then kept fighting until I got the right machine, I'd be dead by now.

Maybe your solution isn't a piece of machinery. Maybe its spiritual, medical, a lot of little things ... You may already have an idea brewing. There may be a little voice speaking to you, telling you what you should do, but you're afraid to change. You're getting by, why bother? But it's still there. Go ahead, go to church, get a breathing machine, start using a scooter, make that phone call you've been putting off, take a cruise, whatever it is, do it. Go from discord to concord; from tension to relaxed.

Have fun....Rick VDL

--○○○○○○○○--

We're in this together. Let's keep up the good work.

--○○○○○○○○--

Fight Back

The following press release was the direct result of the lengthy quest of Rick Kneeshaw and Gladys Swensrud, long time holders of annual passes to both the San Diego Zoo, and Wild Animal Park. It started over two years ago when Rick was pulled out of line and asked to sign a waiver releasing the zoo of all liability no matter what accident might happen to Rick while on park property on his scooter.

Feeling embarrassed, discriminated against, and at risk of losing his home in case of an accident (even if it wasn't his fault), Rick had a choice to make. Either visit the zoo with great risk, or do something about it.



**Rick Kneeshaw and Gladys Swensrud
holding press release (below)**

PPS MANAGER

4

Photo by Lenora Kneeshaw

PRESS RELEASE

Issued by DRLC 11/29/06

San Diego Zoological Society Settles Case Alleging Discriminatory Entrance Policy for People with Mobility Disabilities at the San Diego Zoo and Wild Animal Park

SAN DIEGO (NOVEMBER 29, 2006), The Disability Rights Legal Center (formerly Western Law Center for Disability Rights) announced today that it has reached a settlement with the Zoological Society of San Diego to end what it alleged were discriminatory practices against people with mobility disabilities. The settlement was reached in the federal suit *Kneeshaw v. Zoological Society of San Diego*, Case No. 05-CV-2127-IEG DT (POR), and covers both the World Famous San Diego Zoo and the Wild Animal Park.

As a result of the settlement, the Zoological Society will permanently discontinue its policy of asking people who use motorized mobility aids, such as motorized scooters and wheelchairs, to sign liability waivers or any document regarding their use of such aids in the Zoo or Wild Animal Park. As for previously signed waivers already on file under its prior entrance policy, the Zoological Society has agreed to void all such waivers and never enforce them. In addition, it will notify those who have signed or been deemed to have signed the waivers by putting a notice on its website, its maps, its accessibility guide, and via letters to those who had been subject to the previous policy.

"We are extremely pleased that we were able to reach a resolution with the Zoological Society" said Shawna L. Parks, Director of Litigation at the Disability Rights Legal Center, the nonprofit legal organization that represented the plaintiffs. "The settlement allows people with mobility disabilities to once again enjoy their visits to the Zoo without hindrance or discrimination. The Zoo agreed to do the right thing here."

Named plaintiff Gladys Swensrud, a long time member of the Zoological Society, was very pleased with the result. "Although I'm sad about the time I lost at the Zoo, I eagerly look forward to resuming my visits to the Zoo with my friends and seeing the animals together," she said.

The settlement represents a major victory for people with mobility disabilities who use motorized scooters and wheelchairs. In November of 2005, plaintiffs Rick Kneeshaw and Gladys Swensrud, both polio survivors, motorized scooter users and long time members of the Zoological Society, filed the lawsuit against the Zoological Society claiming that the entrance policy, which mandated that motorized wheelchair and scooter users sign a liability waiver in order to enter the Zoo, unlawfully discriminated against people with mobility disabilities.

Under the Zoo's policy, persons who used motorized wheelchairs and scooters were pulled from line, presented with a series of documents, and required to sign a waiver and indemnification agreement before being allowed to enter the Zoo. The waiver placed all

liabilities and risks on the person with a disability for incidents at the Zoo involving the mobility device, even if the Zoo or its employees were at fault. No other Zoo patrons were subjected to this treatment or forced to sign such waivers in order to visit the Zoo. The suit alleged that the Zoo violated the Americans with Disabilities Act and California civil rights laws, and sought a court order to remove the illegal and discriminatory policy and waiver requirement.

"I'm glad that we were able to convince the Zoological Society that it is the right thing to do to stop this policy. I just wanted to bring my granddaughter to the Zoo. She was looking forward to seeing the elephants, and I was so embarrassed to be pulled out of line, and treated like a criminal in front of my granddaughter," said Mr. Kneeshaw. "I'm glad I got to show my granddaughter that it is important to stand up for our rights and make a change for the better. I can't wait to go back to the Zoo."

The plaintiffs were represented by the Disability Rights Legal Center, a thirty-year old non-profit organization that protects the civil rights of individuals with disabilities.

--○○○○○○○○--

HOW TO GET PNEUMONIA

By R. E. Van Der Linden

Pneumonia, n – an inflammation of one or both lungs, usually caused by infection from a bacterium or virus or, less commonly, by a chemical or physical irritant. Encarta® World English Dictionary
© 1999 Microsoft Corporation. All rights reserved. Developed for Microsoft by Bloomsbury Publishing Plc.

If you want to get really sick, it's an easy thing to do. Just follow three simple steps and you're on your way to the hospital.

Before we begin, I should mention that getting a deadly illness gets easier to do as we get older, and having a disorder such as PPS can make it effortless.

Step one – Provide a happy home for your guests.

In order to find a fertile place to dwell, the virus or bacteria needs your help. One way is to overextend yourself physically. This can be done indoors, but it is particularly effective outside in cold weather. Remember, the object is to weaken your immune system, so fatigue is your friend. Look for signs of increased fluids in the nose and throat. This will provide a landing site for the invaders and supply food for them while they settle in.

Don't overlook the advantage of being emotionally run down. This can be very helpful. It's been scientifically proven that if you are emotionally stressed to the point where you're about ready to crack, you're wide open to invasion.

Another good tactic is to not get the pneumovax. Some doctors recommend it every five years. It protects against 23 of the most popular pneumonia bugs, and it will reduce your chances of getting sick.

If you have a swallowing problem, getting pneumonia can be really easy. You don't even have to go looking for bugs. All you need to do is aspirate (suck food or fluid down your wind pipe) once in a while and a nice warm, sticky soup builds up way down in the bottom of your lungs. Then, bacteria show up out of nowhere and become party animals.

Step two – Invite them in.

Now that you've laid out the welcome mat, open the door. Children can be ideal carriers of the bugs you're looking for. Visit the grandkids. They always have something to share, and they get right in your face. Better yet, bring them in your house and invite them to put their snotty little hands on everything – particularly the phone and TV remote.

Actually, any indoor place with lots of folks is sure to be a hotbed of airborne invaders. But just to be sure, shake hands with everybody and then rub your eye, eat finger foods, and pick your nose when nobody's looking. (I'm going to get letters for that.)

Remember, don't wash your hands, but if you must, use the waterless kind. Plain soap and water is much more deadly to the little bugs, and will greatly reduce your chances of getting pneumonia.

Step three – Don't ask them to leave.

When you feel a cold coming on, keep moving. In fact, don't stop until you can hardly move. A cold can easily turn into pneumonia. So if you feel that dry raspy thing in your throat, or get a runny nose or whatever, don't take those new products they advertise that shorten your cold by one-third. They actually work for most people, and your chance of getting really sick could go flying right out the window.

If you have weakness of the diaphragm and/or intercostals – weakness of the breathing muscles often accompanies swallowing problems – so much the better. It's harder to cough, so once it gets down there, the crud is easier to keep down. A bilevel breathing assistance machine with a humidifier can strengthen the coughing muscles, thin out the crud, and free it for coughing up. If you have the least bit of trouble swallowing and/or coughing, and you really want to get pneumonia, avoid bilevel breathing assistance.

Finally, when pneumonia has at long last moved in to stay, and you are just about a goner, don't be afraid to let them take you to the hospital. After all, we're talking about how to *get* pneumonia here, so I'd be remiss if I didn't tell you the best kind to get. Yes, it's the kind you get at the hospital. It's called pseudomonas and once you have it they can't get rid of it.

But, seriously, folks ...

Up to this point this article was done tongue-in-cheek. However, I didn't write it just for fun. The subject is close to my heart for two reasons.

First: Since being diagnosed with PPS twelve years ago, I've almost ended up in the hospital on several occasions. I avoided it by doing everything I could do to avoid pneumonia.

PPS MANAGER

7

The most recent problem came about from a combination of allergies, sudden cold weather, breathing and coughing weakness, and aspiration due to PPS related dysphagia. (Look for "Hard to Swallow" co-written by myself and Gladys Swensrud coming up in the March 2007 issue of the PPS Manager.)

Second: There are over six hundred polio survivors on my mailing list and as many on my e-mail list. Every month I have the unpleasant task of removing one or two names from the list. Although I don't always know the cause of death, I do know enough to suspect that the most common cause is pneumonia.

I work hard at spreading the word about breathing issues because I know from personal experience that when you're not breathing right, you don't necessarily realize how serious it is. Over time, the downhill slide is so slow that you don't notice you are losing your will to live. You become vulnerable. In many cases, this scenario is preventable.

You, PPS Manager, are a mature person with a lot of life experience to share with the younger generations.

--○○○○○○○○--

FOR IMMEDIATE RELEASE

POST-POLIO HEALTH INTERNATIONAL AWARDS RESEARCH GRANT TO UNIVERSITY OF ARKANSAS TEAM

ST. LOUIS, Dec.19, 2006 –

Post-Polio Health International, headquartered here, announced that it has awarded a \$25,000 research grant to a team from the University of Arkansas for Medical Sciences (UAMS), Little Rock. The researchers propose to determine whether there is a unique signature, or disease biomarker, in the immune system of individuals with post-polio syndrome (PPS) that would enable a more definitive diagnosis of PPS.

PPS is a slowly progressive neurodegenerative disease that occurs many years later in individuals previously affected by paralytic poliomyelitis due to the poliovirus infection. The causes of PPS are unknown but it is characterized primarily by new muscle weakness that negatively affects the quality of life of survivors.

Biomarkers are biological measures found associated with specific diseases. They are useful because they can assist in disease diagnosis or provide a means of monitoring disease development and progression.

The researchers at UAMS recently detected the increased presence of a distinct immune cell population in the blood of individuals with PPS but not healthy individuals, although the number of donors examined was small. The detected cells represent a recently described subtype of T cells, known as regulatory T cells (Tregs).

The research award from Post-Polio Health International will fund a small pilot study that will determine whether development of PPS is associated with increased numbers of Tregs and

whether the Tregs found in individuals with PPS have unusual properties as compared with those in healthy individuals.

“We are very grateful to PHI for their support of this research. Although the research is in its very early stages and our initial results need to be rigorously tested in a much larger group of individuals with PPS, a biomarker for PPS that can be potentially measured in an individual's blood should enable a more rapid and more definitive diagnosis of this debilitating disease.” said Principal Investigator Dr. Rahnema Wahid, Postdoctoral Research Assistant, Microbiology and Immunology Department, at the University of Arkansas for Medical Sciences.

“A definitive diagnosis of PPS is difficult because it is based on past history, which may be lost or incomplete, or dependent on recall. The diagnosis is complex and unreliable because many symptoms of PPS overlap those of other diseases including osteoarthritis, fibromyalgia, hypothyroidism and a number of neurological conditions. Because available treatments are limited, finding a definitive test for PPS would not only help with a diagnosis but would also help develop potentially more effective therapies,” said Joan L. Headley, executive director of Post-Polio Health International.

Others on the UAMS team in addition to Dr. Wahid include Dr. Marie Chow, Professor, Departments of Microbiology and Immunology, and Pathology and Dr. Katalin Pocsine, Assistant Professor of Neurology.

Post-Polio Health International's Research Fund was established in 1995 to seek scientific information leading to eventual amelioration of the consequences of poliomyelitis and/or neuromuscular respiratory diseases. This is the fourth grant to be awarded. Complete reports on the first three research studies – Ventilator Users' Perspectives on the Important Elements of Health-Related Quality of Life ; Women With Polio: Menopause, Late Effects, Life Satisfaction and Emotional Distress; Timing of Noninvasive Ventilation for Patients with Amyotrophic Lateral Sclerosis are available on Post-Polio Health International's website, www.post-polio.org (click on Research).

Post-Polio Health International actively promotes education, research, advocacy and networking among the post-polio community to enhance the lives and independence of polio survivors and home ventilator users.

Post-Polio Health International publishes two newsletters: Post-Polio Health, and Ventilator-Assisted Living. To contribute funds and/or subscribe for the newsletter(s) call (314) 534-0475 or write Post-Polio Health International, 4207 Lindell Blvd., #110, Saint Louis, MO 63108-2930 USA or e-mail info@post-polio.org

--○○○○○○○○--

**If we don't do it,
who will?**

MEETING REPORTS

San Diego Post-Polio Support Group

San Diego Polio Survivor's November 11, 2006 Meeting Notes

By Gladys Swensrud

The first San Diego Polio Survivor's meeting held at our new, Kaiser Permanente/Zion Hospital location on November 11, 2006, was a huge success! Our turn out of 30+ was fantastic, and as a result of the change from the workday Thursday to a more convenient Saturday, we welcomed many new members. Introductions enabled us to greet returning members and gave us an opportunity to learn a little about our new members.

The guest speaker for the day was Carlos Valenzuela from Progressive Orthopedics. Rick Kneeshaw, our group's facilitator, has been a client of Carlos's for many decades; so as Rick introduced Carlos, he expanded upon their friendship and personal relationship along with the professional one they have shared for many years.

Carlos immediately told us his talk would barely touch on his expertise in the field of bracing since the topic for this presentation was his recent trip to the Roosevelt Institute at Warm Springs, Georgia. However, when he did discuss the physiology of bracing, we were all impressed with his vast knowledge and experience. From Carlos's enthusiasm, we could sense that as his professional career in bracing is winding down, he has become more and more interested in the history surrounding his decades' long profession.

Carlos transported us via a slide presentation on each mile of his trip from San Diego to Georgia and back. He told us this excursion had been originally planned to include members of the Escondido polio support group, but for various reasons by the time of departure, all survivors planning to go had dropped out. He felt fortunate to have two of his fellow orthotists from San Diego accompanying him on this journey.

As the program began, Mr. Valenzuela explained that from the Atlanta Airport the drive to Warm Springs is approximately 63 miles. He showed us a slide of the original entrance to Warm Springs, which is no longer used. He said it could be the condition of the historic old entrance and road which prevented it from being used any longer, but the new road was quite accessible. He said during the drive he could sense the emotions a visitor with polio must have felt back in the 1930s/1940s, filled with hope of rehabilitation as they drove past the entrance and onto the grounds.

Roosevelt set the buildings up more like dormitories, rather unlike a traditional hospital. Carlos took us on a "virtual tour" through the facility and along with accompanying slides told stories of the history and of research conducted during the 1930s and 1940s.

Carlos was quite taken with the architecture; he explained that construction of the buildings used extensive columns both inside and outside. It appeared from the slides that it was reminiscent of the architecture of the old, southern plantations.

The Warm Springs Hospital was laid out as a quad, with the buildings all facing one another in a large square. There were rehab areas spread throughout the center of the square where rehabilitation sessions would take place. He showed us an example of a large, cement square with stairs coming up from each side, all leading to a central platform; there were handrails for patients to hold onto to stabilize each step. This was used to teach patients how to use muscles more effectively as they came up or down stairs and/or to practice how to balance more successfully with those motions.

Carlos relayed some of the history of Eleanor Roosevelt's involvement with making the Warm Springs program successful. He also brought up the issue of segregation during that era and spoke of the fact that black polio survivors were not given access to the Warm Springs facility. In order to meet the polio needs of the black community, Eleanor was instrumental in establishing a separate center for African-American victims of polio at Tuskegee College.

It was fascinating to see the slides Carlos provided of the cement pools that stand as a tribute to the warm-water, therapy pools that were so famous of that location; he also had a wonderful pictorial history of the clothes changing areas and of the staging areas for entering and exiting the pools. Carlos felt an emotional tug of the history of that era surrounding him at every turn. He ran through a list of the buildings that still stand as historical monuments on the Warm Springs site: the Roosevelt family cottage where the president lived when he was visiting, the "Little White House" (which was his working office), FDR's secretary's house (where Lucy Mercer lived), the chapel, the hospital proper, etc.

Carlos also discussed some of the many collections that remain for today's visitors to enjoy, like the entire display case of canes that have been received from survivors all around the world. And he chronicled FDR's love of driving on the grounds of Warm Springs. It was fascinating to see the historical photos, which explained the mechanics of how, with the help of hand controls, FDR was able to drive without the use of his legs.

As Carlos brought us into the present and more modern uses for the Roosevelt Institute at Warm Springs, Georgia, he added that today's use of the facility has been expanded to meet the needs of the ever-growing neuromuscular community as a whole. With polio on the fringes of eradication, there are fewer numbers of polio survivors applying for evaluation, yet other disorders like ALS add substantially to the overall impact and needs of the neuromuscular population.

When asked about the costs incurred for his entire trip from airfare to room and board, Carlos responded that the costs were very reasonable. It ran approximately \$800 from coast to coast, start to finish. The nightly room fees on the Institute's grounds were in the range of \$60, and the costs for food were extremely reasonable.

Carlos closed with his recommendation of two books, FDR's Splendid Deception by Hugh Gregory Gallagher and POLIO: an American Story by David M. Oshinsky.

San Diego Polio Survivor's 2006, Holiday Party

By Gladys Swensrud

We celebrated our Holiday Party this year at our new Kaiser Permanente/Zion Avenue location; the new room was an additional highlight, which made our gathering all the more successful! Kaiser opened up the partition between our room and an adjoining room, pushed tables out of the way and arranged the chairs in a friendly circle fashion so everyone could easily see and visit with one another. The Kaiser crew is amazing, and we thank them for their help in making us feel welcome in our new setting.

Even though we threw people a curve this year with the recent change in our meeting day and location, we had over 20 people attend, each arriving with a potluck lunch item to fill our luncheon table, and with white elephant gifts in hand. We, once again, were pleased to welcome new people discovering our group for the first time. As the room filled with friends and laughter, the gift table bulged with surprises, and a great spread awaited us at the buffet table.

Special thanks to Mike Blaziak who played his violin again this year while everyone was busy greeting and meeting one another. We sang carols, laughed and found this particular get-together a perfect opportunity to get to know one another better. Many spouses attended, and it was fun to see the "other half" of many of our members.

Steve Goldman, once again, was the honorary emcee for our white elephant gift exchange. Steve's witty sense of humor lends itself perfectly to this type of activity. He kept the chatter going with his humorous description of each gift that was opened, shared and stolen.

This was also our first real opportunity to test a potluck strategy for future meetings, which our new meeting room and times allow, and we found everything so accessible and easy to use that we will be planning potlucks for whenever members' desires dictate. Contact Gladys Swensrud at 858-271-9288 to sign up for dishes or desserts for our next meeting, Saturday, January 13, 2007.

The telltale sign of a great gathering is when everyone lingers long after the party is over. We had the room for three and a half hours, yet that wasn't long enough to share all our thoughts and stories with one another. We found ourselves exchanging telephone numbers and addresses, and this social gathering left each of us with a feel-good emotion, lingering long after goodbyes were said.

Our next meeting will be on Saturday, January 13, 2007, and the scheduled topic will either be handicap accessible home modifications or useful handicapped tools to use around the home. Anyone within the greater San Diego area is welcome to attend; we hope to see a full room!

___ **The next La Jolla meeting:** ___

PPS MANAGER

12

January 13

Regular meetings (until further notice) are at 10 AM on the second Saturday of odd numbered months at: Kaiser Permanente 4647 Zion Avenue San Diego, CA 92120.

For more information call **Rick Kneeshaw** 858-566-4016 or piecon@mindspring.com

Or go to <http://polio.home.mindspring.com>

--00000000--



Photo by Gladys Swensrud – at SD Holiday Party 2006

Rest in Peace Bob Hudson

Bob passed away December 30. He was one happy guy and an inspiration to us all. We miss you, Bob. We're here for you Alice.

--00000000--

Escondido Post Polio Group

___ The next meeting: ___

February 13

Regular meetings on the second Tuesday of even # months from 1:00 to 3:00 at Joslyn Senior Center, Dorothy Boeger building, 728 N Broadway, Escondido

For more Escondido info. call Mary Clare at 760-741-5075 or postpolio@cox.net

COACHELLA VALLEY

PPS MANAGER

13

POST-POLIO SUPPORT GROUP

Since the scheduled speaker was a no-show, the December meeting was an impromptu discussion of personal stories of polio, aided by a couple traveling through California in their RV. The husband had polio and was interested in sharing knowledge of post polio. The meeting was shortened by an impromptu urge to lunch at a local restaurant to celebrate the holidays. It was quite successful.

Kurt Sipolski

_____The next meeting:_____

January 12

February 9

2nd Fridays at 10 AM at Portola Community Center, 45-480 Portola Ave, Palm Desert CA Park in rear.

For information, contact Joe Camaya stan-n-ollie@msn.com, phone (760) 365-3587

HEMET AREA POLIO SURVIVORS

Hi Everybody.

The Christmas party was really fun. Lots of food, warm and friendly, sing-along, ornament exchange, we pretty much ignored PPS issues altogether. What can I say? If you weren't there, you missed a good one.



Melanie Alredge from Progressive Medical is planning to attend in January, so it should be a good one.

We might have a speaker at our February meeting, too. Not sure who yet, but there are a couple of possibilities.

Have fun ... Rick

Note:

Long-time member Ramona Orton is planning to move far away. She has a scooter she'd like to give away.

Free three wheel scooter, Cauffeur brand, good battery(s), needs work, Hemet (951) 652-2718 I (Rick) can deliver it locally.

____ Our next HAPS meetings are: ____

January 17

February 21

Regular Hemet meetings are at 11 AM to 12:30 on the third Wednesday of every month at: Sun West, 1001 N. Lyon, Hemet. For more info call RickVDL (951) 926-5492

Riverside PPS Group



Message from Betty McFarland, co-facilitator Riverside PPSG

Another year has ended with many memories for all of us. We have learned some things about our physical problems and established many new friendships. All in all, we have been blessed in many ways this past year and thankful for every blessing. With the new year our health will continue to change, and there will be new challenges, and more reasons to get together and share as we continue the search for answers.

From our PPS Group to yours, we send our Best Wishes for Happy, Healthy, and Awesome New Year. – Betty McFarland, co-facilitator.

From Judy Mahoney, co-facilitator Riverside PPSG

With each year the bonds of our friendships are made stronger. Bryan and I enjoy having the PPS meetings in our home, and I am grateful for all the smiles and encouragement we receive

PPS MANAGER

15

every time we get together. A very special thanks to Rick & Sandy Van Der Linden for their encouragement and support, and of course the music! Thank you Eddie Ceseña for joining us at our Christmas luncheon with your guitar and helping to make our day so delightful. I wish we could package that music and the enjoyment we all felt that day and send it in the newsletter to every reader!

With Betty I wish for you the best new year yet, and invite you to our next PPS meeting, which will be February 17, 2007 at 10:00 am.

____**The next Riverside PPSG meeting:**____

February 17

Riverside PPSG Meetings: third Saturday of even # months at 10 AM. - at the home of Bryan & Judy Mahoney, 3465 Ramona Drive, Riverside CA. For more info. contact: Judy PPSRiverside@aol.com (951)788-9310 or Betty McFarland (951)243-6991
bbooplink@aol.com

Big Bear PPS Group

For information contact Marsha at (909) 878-3092

High Desert PPS Group

The High Desert PPS Group met Nov 14th for our regular meeting with a wonderful and encouraging guest speaker, Dinah Lambert RPT who & owns and operates Comprehensive Physical & Aquatic Therapy Center in Victorville. She issued a challenge to all present to stop by for an evaluation and trial of aquatic exercise. We all know water therapy is the best for our poor muscles!

Kay

____Next meetings:____

January 9

February 13

Regular meetings: Second Tuesday of every month. Location varies.

PPS MANAGER

16

For information contact Vi at (760) 949-6775, or e-mail BillHerold@aol.com

Polio Survivors Plus Of South/West Orange County

To help ring in the happiest of holidays, all polio survivors, their family and friends were invited by Polio Survivors Plus (PSP) to join with others and to participate in the 98th Annual Newport Beach Boat Parade on the evenings of December 13-15, 2006. Tasty treats were served and while everyone came bundled in layered clothing, complete with hats and scarves, the weather was quite temperate. Music books were provided and traditional songs heightened everyone's merriment complete with guitar accompaniment. Boats and yachts of all sizes were decorated with lights and some with animation. The parade winners are scheduled to be honored on January 19, 2007 at the Balboa Bay Club & Resort:

Tributes to peace and harmony are continuing into this near year. It continues into the new year with the Board of Orange County's Polio Survivors Plus wishing everyone a healthy and happy new year.

It continues with yet another special performance for polio survivors, their families and friends; and people with disabilities. On January 11, 2007 at 2 p.m., Boston University's A Cappella performers, Kol-Echad (which means, "One Voice") will perform at the Regency, 24441 Calle Sonora in Laguna Woods, CA 92637-7700, under the musical directorship of Adam Riley, grandson of PSP's co-founder and a senior in Engineering.

There is no charge for the performance, but an RSVP is requested prior to that date to ensure proper accommodations.

PSP's January 24th program at 1:30 to 3:30 p.m. in Clubhouse 3 of Laguna Woods Village, features Attorney Kim Hubbard who heads the Financial Abuse Specialist Team (FAST), a multi-disciplinary group of public and private professionals who volunteer their time to advise Adult Protective Services (APS), the Ombudsmen, law enforcement and private attorneys on matters of vulnerable adult financial abuse. As the FAST Coordinator, Kim provides education on financial abuse to the public and other professionals, while working with legislative groups to create and strengthen the laws available to protect the vulnerable adult population.

There is also no charge for admission to this presentation, but an RSVP is also requested so gate entry authorization can be arranged in advance.

Next meeting: _____

January 24
February 28

Regular meetings are held on the fourth Wednesday of each month, 1:30 to 3:30 PM. At Laguna Woods Village's Clubhouse 3

PPS MANAGER

17

23822 Avenida Sevilla, Laguna Woods, CA

For information and to RSVP, contact:

Sue Lau at (714) 639-7497 or e-mail Maliebchen@aol.com

--00000000--

LETTERS

Hi Rick,

I would like to recommend a book that I recently read. The title is "Polio: An American Story" by David Oshinsky. It has won the 2006 Pulitzer Prize for History. This is a must read for polio survivors and history fans.

I have a question for you. When people with PPS have major surgery, does the PPS create added risks to the patient? What about after surgery – during rehab?

Happy Holidays and keep up the good work.

Fred.

Fred,

Thanks for the recommendation. I'll be sure to pick it up.

Yes, surviving polio leaves us unusually sensitive to anesthetics, particularly those that paralyze our muscles. We require two to four times less and it can take two to four times longer to recover.

There are a couple of very good reports on the subject. One is by Dr. Richard Bruno, the other by Selma H. Calmes, M.D. Giving this information to your anesthesiologist and doctors before surgery can save your life. I'll mail them to you.

Rick

Rick,

Please accept the enclosed check as a small token of thanks for doing such a great job with your newsletter.

Adrienne Marks, Alice Marks, and Deborah Hodges.

Dear Rick and family,

Thank you for our PPS newsletter. I look forward to receiving it to not only learn the latest up to date ... [information] making us a little wiser in our choices, but also I appreciate reading about our members and the different meetings. It's a nice way to keep in touch and I am glad you help us do this!

Enclosed is my contribution to help keep our news coming!

May your Christmas be a merry, happy one, and your New Year a happy, merry one, indeed!

May the New Year be full of God's blessings for you and yours.

In appreciation –
Elizabeth Holgren

Thanks Elizabeth. Your good wishes mean a lot to me. May 2007 be your best year ever.

Judy Sander (One of the founders and the original leader of the San Diego PPS support group) wrote to let us know that she is doing fine, though her family suffered a series of tragedies in 2006.

Judy is still living in the beautiful Sedona, Arizona area.
We pray 2007 is good to you, Judy.

--○○○○○○○○--

There is no tree in the forest that is straight, though all are reaching up for the light, and trying to grow straight.

-- From The Gospel of the Redman --

--○○○○○○○○--

THANKS

Thank you for reading the PPS Manager Newsletter. And, thanks for your help and your words of encouragement.

Special thanks to Sandy Van Der Linden for stapling and attaching the labels. Ann Howell for your graphics expertise. Thanks to Floyd & Minna Meyer, Fred & Pamala Munson, Clairene Chessman, Bob & Mary Lucas, A.M. Marks, Edith Fuller, Jessie Paarman, Joann Bangs, Betty Waiswilos, the Riverside PPS Support Group, Elizabeth Holgren, Pat & Tom Sampsell, and Don & Carol Baisch. Your contributions keep this thing alive.

--○○○○○○○○--

The PPS Manager is published every other month by RE “Rick” Van Der Linden and is presented as management ideas.

**To give financial help
Make check payable to:
RE Van Der Linden
34711 Lyn Ave
Hemet, CA 92545**

To submit ideas, writings, or commentary, write to above address, E-mail PPSman@aol.com,

PPS MANAGER

19

or call Rick at (951) 926-5492

Information contained in this newsletter is not intended to be a substitute for proper medical care.