

January

The Southern California

PPS MANAGER

2012

Dedicated to being our best with Post-Polio Syndrome

www.ppsmanager.com

FROM THE EDITOR

Hi Fellow PPS Managers,

Once in a while I have to remind myself of why I choose to refer to us as PPS Managers. The arrival of a new year seems like a good time to think it over.

For those of us with PPS, managing is a full time job. For those kind souls who choose to help us, PPS management is at least a part-time job. We learn from experienced professionals, and from each other, and then we put what we learn into practice managing a body restricted by the late effects of polio.

I've been known to sign my name "R.E. Van Der Linden, PPS Manager." It's not that I'm particularly proud to be one, it just happens to be my un-chosen vocation. So why not accept this thing I can't change.

While accepting this change, we should remember that polio is something that happened to us, but it's not who we are.

R.E. Van Der Linden, PPS Manager

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By Gladys Swensrud

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Breathing & Sleep/2011 in Review

By Gladys Swensrud

Those of you who couldn't attend Breathing & Sleep/2011 on October 29th were much missed. We had 127 people attend, and it was an invaluable day of post-polio information sharing at the prestigious Salk Institute for Biological Studies in La Jolla.

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You could have heard a pin drop in the auditorium throughout the entire program. Our third event was almost totally focused on PPS this time around, which was by design. Dr. Han's presentation was all about polio in China and how it corresponded to polio in America. Everyone was quiet as a church mouse listening to his every word. Dr. Benditt's presentation was the absolute best overview of PPS breathing I have ever heard...and as most of you are fully aware because of my 10 years of PPS respiratory compromise advocacy, that is really saying something! Dr. DeMaria, U.C.S.D. cardiologist, was a character, filled to the brim with Sleep Disordered Breathing information linking it to heart failure and stroke. Everyone sat wide-eyed and enthralled with his presentation as he connected all the dots. And both of ResMed's RRTs (Angela King and Karyl Scott) talks were wonderful for clinician and patient alike. They very gracefully straddled the line from professional to general public understanding of equipment and its uses perfectly.

The auditorium was warm this year, so no chilly moments...what a delight! The food was plentiful and delicious. During the break we took a group polio survivor picture in front of a painting of Dr. Salk in the Salk Trustee's Room. That was one big highlight of the day for all of us. Corralling 40 (give or take) survivors into a still photograph was a hoot! I am sure you can pretty much visualize it!

Polio survivors throughout the United States will be forever indebted to the Salk Institute for Biological Studies and ResMed Corporation for their generous funding of all three Breathing & Sleep Symposiums. Oftentimes polio survivors feel as though we are tilting at windmills in our efforts to educate the world about issues related to our aged disease, but the Salk Institute and ResMed Corporation have done more than merely listen...they have spoken loudly by supporting us as we attempt to educate not only others, but as we continue to educate ourselves as well.

To view all three events, go to www.poliotoday.org, click on the Videos tab toward the top of the page and a dropdown box will appear allowing you to select the year of your choice to watch. It is not only well worth a bit of your time, but the information could actually be a life changing experience in more ways than one!

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Pray, not for God to cure you but to help you help yourself.
Kirk Douglas

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FROM TEN YEARS AGO

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[The following is a shortened version of an article first published in the February 2002 issue of the PPS Manager newsletter.]

Everything You Ever Wanted to Know About Owning a Home Spa

(Okay, Everything I Know about it)
by Rick Van Der Linden

As with many polio survivors, PPS was ushered in with a run-down feeling -- the feeling of "getting old before my time." My first reaction was that I must be getting lazy in my old age, so I started a rigorous exercise program. It wasn't long before I had aching muscles. I recognized the need for massage therapy, but it was too expensive and not available on demand. Besides, I was too shy to even try it. Solution -- a home spa.

My first spa cost \$250.00. I moved it myself (with a lot of help from my friends), spent about \$125.00 for a concrete foundation, \$100.00 for the electrical connection, and \$650.00 to replace the pump/heater package. I didn't mind the repairs and other expenses because it had an acrylic tub which will last many years. (Later I traded a bass guitar for a privacy fence.)

Stretching is easier in the spa, and was seldom skipped. On a cold winter evening I could watch the snow fall through the mist rising from the hot bubbling water. On a hot summer day the water, set to a lower temperature, was refreshing.

At first the spa was a wonderful luxury, but as time went by and PPS reared it's ugly head in full force weakening muscles became more sore with less effort and the spa became a necessary part of my management program.

You probably know how difficult it is to shop for equipment and set up new procedures when you're fatigued. Fortunately, the months spent learning spa care and maintenance, and massage and stretching procedure were out of the way before I really needed them. With this in mind I share with you all I have learned about spas.

Advantages of having a home spa

- PPS related cold intolerance is washed away.
- We weigh about 90% less when we are suspended in water -- what a relief.
- Even though we may do very little exercise, we still work hard to perform our daily minimum activities and lactic acid still builds up in our overworked muscles. The jets massage away the burning acid.
- Stretching improves range of motion and reduces stress on joints. It is much safer when the muscles are warm and relaxed.
- Stretched muscles help prevent skeletal injury in the case of a fall.

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- Kicking your legs and waving your hands through the water can provide a little bit of aerobic exercise with less overall stress.
- It's very relaxing. Less mental stress = less physical stress = less pain and fatigue.
- Your spa is available any time you need it.

[Here I leave out ideas on selecting and installing a home spa. The complete article is online at the PPS Manager site.]

Recommended temperature

Based on fifteen to twenty minutes spa time: Winter - 98 to 100 degrees, Summer - 96 to 98 degrees. The hotter the water is the less time you can spend in it. If you have rubber legs or feel fatigued when you get out, either you were in it too long or it was too hot.

My routine for PPS management

Set vents and open spa before showering.

- 1) Relax in spa and let muscles warm up.
 - 2) Massage. With air jets running move each muscle across convenient jets.
 - 3) Stretch. Shut off jets if you want to (I like it quiet or listen to soft music). I stretch the back of my legs, quads, hips, arms, neck, back, the works. The stretches you do depend on your needs and abilities and/or the advice of your physical therapist. A good reference, however, is the exercise video from Warm Springs Georgia called "Aquatic Therapy for Polio Survivors", Part 2 of the "Wellness for the 90's" series. (800) 235-2156.
 - 4) Relax. You may want to do some more massage.
- Total time including shower and dressing - 1/2 hour.

Conclusion

As a PPS manager, a home spa might be one of the best things you can do for yourself. Proper use can improve mobility, reduce pain, and relieve stress better than any other treatment, professional or otherwise. I wouldn't be without mine.

Enjoy!

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MMJ (Medical Marijuana) A Research Project Part 2: Who Uses MMJ? By RE Van Der Linden

On the Internet and in interviews I learned about people who use marijuana for various medical conditions such as glaucoma, back pain, nerve pain, MS, neurological disorders, and the effects of chemotherapy. All are mature, sensible adults who had tried traditional medications and found marijuana effective without undesirable side effects when used in moderation.

[The following four people are PPS folks who wrote or called in response to the first article. The names have been changed to protect the innocent.]

Larry in La Jolla

Larry had polio as an infant, leaving him with a weakened left leg. 40 years later, after a long career with the Government, his weak left leg caused him to overwork his right leg as PPS set in. In response, Larry's neurologist started him on pain medications.

Due to the side effects of prescribed narcotics, Larry had to take several other medications to treat things like dry mouth, constipation, and sleep disorder.

In 2008 Larry took advantage of California's Compassionate Use Act, and replaced the narcotics and other medications with medical marijuana.

Now Larry lives comfortably with his wife, who has a professional career. Larry's daughter, 22 year-old neurology student, graduated June of 2011 and go on to post grad in 2012. His son, 20, is in college.

"I couldn't have done it without my family's unconditional support." Larry said. "They all saw the difference between Rx pill and MMJ therapy efficacy on me. Now I can go to theater to enjoy and

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watch movies with my family, unlike back in the pill days where I would go to theatre intending to watch but end up sleeping through it. There were a lot of times I'd get an elbow poke from my right and left side coming from family members to keep me from snoring while the movie is running."

Larry said, "About a year after replacing narcotics with MMJ, I noticed I could smell my food again. Narcotics had taken so much from me."

Larry grows his own cannabis and processes it into edible form. He tried various other methods and, like many others, finds the edible form of the natural plant to be the best way to use MMJ for pain relief.

He finds that he can function fine while using the product and that, while it doesn't have the same kind of pain relief effect as narcotics, "it makes me want to relax so I don't do the things that make my legs hurt."

"There's no intoxicating effect -- nothing like alcohol," Larry said. "Once you get used to it, the effects are easy to handle and don't interfere with daily life."

Mary in Mira Loma

I wanted to share my story with you about MMJ, first of all, thank you for putting out the excellent write-up on the subject. It is such a hush-hush subject for the most part. Most people don't talk about it but the number of patients Medical Marijuana doctor sees in one day, speaks volumes.

My story is: I can't tolerate pain meds, the last pain med I could take and did get some relief from was Darvocet. This drug, in the past year, has been taken off the market. Dangerous due to its contents or some FDA BS, so I was left with nothing for pain but Tylenol.

I have had a Medical Marijuana card for the past 2 years. I do use it in the privacy of my home and am responsible with it. The stuff helps me so much with my nausea and stomach problems, so I feel good and can enjoy the food I am eating without feeling nauseous afterwards.

I also take it for PPS pain, but I have to say mainly for the stomach problems. I don't know what I would do without it. Plus I don't get the munchies, I only smoke or take a capsule when needed. The main thing is to treat this with respect.

In my opinion, [from the standpoint of social use] it is so much [less harmful] than alcohol, in so many ways. If the Feds would just legalize it, the economy would turn around, especially in states like California that are broke. I feel we are going to see legalization in our lifetime but the laws have to be written and refined and enforced.

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I hate to say it, but there are younger people who get a card for headaches just to get high. But then I have met younger people with PTSD from their service in the war that get desperately needed help from Medical Marijuana.

And then there are people like me with chronic illnesses like PPS pain. It helps lift my mood and helps the depression. Especially in the long, cold winter months where the days seem so much longer than in the summer when we feel better.

I am a proud card carrying member. I don't broadcast it and I totally respect this natural remedy. It makes me a better person and a better spouse.

By the way, my spouse fully supports my using MMJ.

I feel they should give it to all the inmates in the jails and prisons, make them all more passive and less hostile. What a world we live in!!!

I am so happy you started this discussion. I look forward to reading other readers' input on the subject.

Tom from Temecula

- 1) He thinks it's worth trying carefully, first in small amounts. It may take a few times to get benefits.
- 2) He does seem to get temporary relief from joint pain, seems to increase blood flow and promotes activity such as stretching and swimming. Fatigue late in the day (i.e. "hitting the wall") seems to be often relieved and he can continue working another couple of hours. (His prescribing doctor recommended a bedtime dose but he finds other times can be most useful.)
- 3) Dosage and route of administration are everything.
 - Too much causes unwanted anxiety and increased heart rate. Smoking or inhaling doesn't work for him. He is longtime user with very good general health, with healthy heart rate/blood pressure.
 - He uses cooked medicine exclusively (smoking/inhaling unhealthy). Recipes abound on the Internet.
 - He finds store-bought edibles way too strong -- he buys relatively inexpensive medicine, 70% "shake" and 30% bud, uses a scale to measure standard amounts for cooking, cooks overnight in a crock pot with grape seed oil and water, freezes then skims oil off the top for cooking. Cost: maybe \$80 a month.

When asked if his family and friends approved, Tom replied, "My family is okay, my mom actually was visiting one time and it made her a little uncomfortable but she said it was okay if it makes me feel okay. Brothers and sisters don't have a problem. I would not tell anyone I work with. That is my

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biggest concern potentially is my employer, they say medical evaluations are private but you never know.”

Bob from Bakersfield

I had bulbar polio as a child, just before the vaccine came out. I was okay for about 40 years, but for the past 15 years I've had problems throughout my body, mostly upper body weakness and pain. I tried a few mild pain relievers and found that they worked okay but made it too easy to hurt myself by doing too much.

For a decade I managed the pain by using assistive devices and resting frequently. That worked fine until my wife and I realized that the chronic pain was making our lives miserable. When no amount of rest relieved the pain I became irritable, anxious, and often depressed.

I'd heard about the possible benefits of medical marijuana and even tried smoking it now and then but didn't like the high feeling when I took just a little too much. Plus, it just didn't seem like a good thing for my lungs.

Not long ago I decided to get a “green card” [prescription for medical marijuana] and learned about a better way to use MMJ, which is ingesting it in cookies or brownies or other foods. Although I haven't been using it for very long, it seems to be helping so far. My wife says I'm more relaxed and easy to get along with.

As for pain relief: I don't think it works like other pain medications. Yes, the pain seems to be reduced, but I know it's still there so I still use assistive devices and rest often. Part of the benefit comes from the euphoria produced by one of the active ingredients. Though this effect is slight in medical dosage, there is still a feeling of wellbeing that I haven't felt in a long time.

Thank you for opening a discussion on this subject.

Bob

And then there's:

Montel Williams

This well-known TV personality, suffers from the pain of multiple sclerosis. He found prescription medications too harsh, addictive and fraught with troublesome side effects. He replaced them with cannabis, and is now a proponent of MMJ.

Montel recently made a trip to Israel to see first hand what doctors there are doing regarding MMJ.

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[Excerpts from the CBS/AP report:]

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In Israel, certain doctors can approve cannabis prescriptions and dispense them to patients, said Itay Goor-Aryeh, the head of the pain management unit at the Sheba Medical Center in central Israel. He said that while marijuana use is carefully regulated, many doctors prefer prescribing it to patients who qualify because it is "the lesser of evils."

"Those patients, if they do not get cannabis, they will get morphine-like drugs and other harmful drugs," said Goor-Aryeh.

"For me, there is nothing else that can do what it does," Montel said. "It helps me suppress my pain... When I am not using cannabis, I am thinking about my pain every 45 seconds."

He said the drug had been "vilified to substantiate the false reason why it was banned in the first place," and that he hoped it would one day become a regular prescription drug.

"There are chemicals within that plant," he said, "and some of the leading science on where and how those chemicals work is being done right here in this country," referring to Israel.

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Mr. Williams uses marijuana every day and regularly appears on talk shows endorsing its use. In a recent Dr. Oz show, he spoke of his close call with suicide before he added MMJ to his MS management regimen. In another Dr. Oz episode they discussed its medical benefits, and joined a panel of influential people on both sides of the issue of the legal use of cannabis.

[Some interesting points made on the Dr. Oz show:

- 1) 3 of 4 Americans are in favor of legalizing MMJ.
- 2) A February 2010 UCSD study concluded that smoking marijuana does not cause cancer and is, in fact, anti-oxidant.
- 3) After 10 years of MMJ use, imaging tests show that no new plaques have formed in Montel Williams' brain indicating the MS is being controlled.
- 4) In spite of California being the most liberal in issuing MMJ prescriptions, studies show that use among children has decreased.
- 5) 4 states are now taxing the sale of medical marijuana.
- 6) 40% of people with MMJ prescriptions are addicted to other drugs. (Unknown: the percentage of people prescribed MMJ to get off more harmful drugs.)]

Mr. Williams said that Opium based drugs such as Oxycontin, and other prescription drugs stole his life from him and medical marijuana helped him get it back. While he admits that it may not be for

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everyone, there is no doubt that he passionately supports a person's right to try it for medical applications.

Should I try it?

I still hear my mom saying, "Just because he jumped off the bridge ..." But then, I asked the same question in Part 1 of this series, and no one wrote in and yelled, "DON'T DO IT, RICK!"

And, what about Dr. Oz's objections: a 10% chance of getting mildly addicted to something without side effects as opposed to the enormous rate of serious addiction to opiates?

And what about THC and the heart? Is heart *stress* the deal breaker? That may depend on the strain of cannabis. [More on that in the next episode.]

And finally, I'm against pain medications. I want to know when I'm hurting myself. So why am I even considering MMJ? Because after almost 20 years of managing my way in and out of pain without drugs, I can see that there is a breaking point. Maybe there's a way to bend just enough without breaking?

One big question, however, is: How, exactly, does MMJ treat pain? Mr. Williams says it relieves nerve pain, and others say it relieves PPS pain. But there are still questions left unanswered because I have muscle pain all over and neuropathy in my limbs. Can it relieve one, the other, or both?

If you have a question, a comment, or helpful information, please call or write the PPS Manager.

To be continued ...

MEETING REPORTS

San Diego Post-Polio Support Group

November 12, 2011 Meeting

Reported by Gladys Swensrud

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Thanks to all the brave souls who "swam" to and from yesterday's meeting! I don't remember driving rain like that in San Diego since the drenching we took during Breathing & Sleep/2010 (smile). Getting home at noon was a challenge regardless of the direction you were traveling from Kaiser on Zion!

We had a relaxing gathering with the normal welcomes, a quick, wrap-up summary and review of Breathing & Sleep/2011, complete with discussion on Dr. Han and his Chinese presentation on polio in China, and details about: 1) the progress Rick Kneeshaw is making post his surgical C2-C5 spinal fusion and 2) how Don Baisch is holding up after Carol's serious fall 18 days ago. We all missed you, Rick, Lenora and Don!

The remainder of our meeting was spent in open discussion while we worked on greeting cards for Dennis Stubbs, the Maine polio survivor highlighted in a posting in late September by Salk's Webmaster, Liz Hincks. We don't often enough just take the time to simply sit and talk, so the opportunity was enjoyed by all as our topics were varied and pertinent.

Special thanks from all of us to Paula Lambert for hauling all the art supplies to our meeting and putting together wonderful cards for mailing along with providing all the supplies needed for each of us to create our own meaningful, personal notes. Thanks as well to Carol, John and Barry Stoveken for taking the time and trouble of stopping at the donut shop and Starbucks on their way down to provide us with absolutely yummy, fresh donuts and piping hot Starbucks, which carried us through the morning!

December 10, 2011

Thanks to everyone who attended this year's **Christmas party** at Rick and Lenora's. The Kneeshaws' co-hosts, Kathy, Tyler, Emma and Andrew, were all involved in making everyone feel welcome and all were gracious hosts!

Also, special thanks to Nice/Naughty, Steven Goldman, and his elf helpers, Emma and Andrew. You each made our gift exchange run like clockwork. Everyone had their favorite gift of the day, but it looked to me like the biggest winners were the two wine gift sets (smile). Each one quickly reached the three-touch threshold in record time! Also big thanks to Marilyn and George Loba for bringing "helper gifts" for Emma and Andrew. It seemed like that was the best part of their afternoon.

At everyone's request, I'll be posting the main dish casserole recipes at PT.org as soon as I collect them all. Funny how wonderful all the food tastes when everyone brings something to share.

As noted in earlier emails and discussed again at today's gathering, we will be selecting a new

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meeting location for 2012. All Kaiser community meeting rooms have been closed for the upcoming year. We will hope they will resume their schedule in 2013. We have requested to be kept on Kaiser's Community notification list.

In the meantime, everyone agreed to scout for a new location. Several good suggestions were tabled at today's party. If you have an idea for a central location where we might meet in 2012, please let us know ASAP. We will be sure to notify everyone if a January 14th meeting is in the cards. Regardless though, please place the North County group's next meeting date, February 14th, on your calendar, and plan to attend if at all possible. Dr. Bunyak, Encinitas Physical Medicine Physician, will be the guest speaker. We'll be sending out a reminder closer to 2/14/12.

It was requested that I share the hyperlink for Boca Raton's "Second Time Around" newsletter. Please link to: <http://postpolio.wordpress.com/newsletter>. Their December edition is definitely worth a read. Hoping you will take the time to give it a look-see!

Thanks to everyone for attending and making today's event memorable! Any time we are together we create priceless memories, which will be held in our hearts for years to come. We are all very proud to be members of the San Diego Polio Survivors!!!

Merry Christmas and Happy New Year greetings extended to all!

Gladys Swensrud and Rick Kneeshaw

___The next San Diego meeting:___

January 14??

Regular meetings are at 10 AM on the second Saturday of odd numbered months at: Kaiser Permanente 4647 Zion Avenue San Diego Classroom #2

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

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

San Diego North
Post Polio Support Group

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North San Diego PPS Group joined the SD group for the Holiday party at Rick Kneeshaw's house. See Gladys Swensrud's report above.

 The next meeting:
February 14

Regular meetings on the second Tuesday of even # months from 12:30 to 3:00 at Joslyn Senior Center, Dorothy Boeger building, 728 N Broadway, Escondido For more info. call Marilyn Loba (760) 745-2787 or email ppsnorthsd@cox.net

HEMET AREA POLIO SURVIVORS (HAPS)

Our November meeting was a fun interaction. We discussed my latest research project and other PPS issues.

Ann Corey had some interesting things to add. One is the fact that she wears a custom fitted Spencer corset. This device laces up to hold in the abdomen, reducing the dead weight of internal organs. Ann explained that, just like any other polio weakened muscle group, our abs might need help. The corset prevents the weight of the internal organs from pulling down on the diaphragm, therefore reducing breathing effort.

This discussion came about as a result of our discussion of the November issue's MMJ article in which I told of Dr. K's observation that, in his experience, weak abdominal muscles are a common occurrence in polio survivors.

Also discussed was the possible advantage of MMJ as regards living with the constant presence of pain below the level of 7 or 8 on a scale of 1 to 10. We've lived so long with this subliminal pain that we may not recognize the effect it has on our stress level, personal lives, and relationships.

Though Ann is morally against the use of cannabis, she admits that there may be a positive side to the story.

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If you can't make it to meetings for health reasons, I understand. But, if you can but choose not to, you're really missing out on some fun and lively talks. Our candid discussions leave nothing to the imagination and go way beyond what I write here in this column.

We had to cancel the December Christmas party. Bunny broke her leg on Thanksgiving Day and was in the hospital recovering from surgery. I had a cold/cough, Betty Cameron was sick, and Mary Lucas broke her arm. Bill isn't doing so hot either. Most of the folks I spoke to were relieved to have the day off, as it is so difficult to do anything in this cold, cold weather we've been having.

Let's look forward to a new year of sharing and helping one another be better PPS managers.

Update on Bunny:

Bunny is going to be spending a couple of months at Reche Canyon Rehab at 1350 Reche Canyon Road, Colton, CA 92324 (909) 370-4411 It would really cheer her up to have company, a card, a call, anything.

Have fun, Rick VDL

____ Our next **HAPS** meetings are: ____

January 17

February 21

Regular Hemet meetings are at 11 AM to 1 PM on the third TUESDAY of every month at:

Sun West, 1001 N. Lyon, Hemet.

For more info call RickVDL (951) 926-5492

or Bunny Smith (951) 766-7118

Riverside PPS Group

We cut back on our festivities this year, and still had a very nice time.

Regina brought hand-crafted gifts for everyone, always done with love and beautiful creativity. She pointed out the December 17 *Press-Enterprise* article "Boy Sends 800 Cards to Needy," describing how 7-year-old Jack Kenney, who suffers hearing loss, was inspired to design cards for people who need hope and the love of God's word in the holiday season. Regina has a few things in common with this boy – she has hearing loss, is a gifted card designer, and has a heart for people. Everyone

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took a copy of the article.

It was so good to see Dona at the meeting, as a few difficulties have kept her away of late. She broke her left leg this year (the right leg in 2004) – now has bars in both legs! While the doctors will say “six weeks” to heal a broken femur, with the polio it can take 8 to 9 months.

You have to find ways to keep yourself from atrophy during that time. Dona doesn't stay down for long, and we were so glad to see her walk in, although unsteady on her legs – but does use walker or cane at home as needed. She will use a wheelchair for family outings at Knott's Berry Farm and Disneyland.

She said she really appreciated the great series of articles from Gladys in *the PPS Manager*, and hopes Rick will keep the newsletter going.

Lorraine Hartik's former Kaiser PPS doctor, Elizabeth Blair Smith, now a Kaiser San Bernardino Administrator, will be going to India with her husband (a nurse with Veterans Hospital Loma Linda) to inoculate children under a program sponsored by Bill Gates. She credits Lorraine with putting her onto the need for continuing the worldwide drive against polio.

After lunch, Bryan treated us to his one-man performance of “Marley's Ghost.” It was enjoyed by all, and we thank Dona Scandura, former President of Riverside Children's Theater, for giving the show a high critical rating

Some polio items: Betty McFarland is improving, although slowly, from a torn meniscus in her right leg (4-5 weeks ago). She is beginning to cut back on her many activities, no longer doing the boutique for her church, but still active with other services, and raising grandson Jonathan.

Scoliosis was the issue of the day. We learned that in her youth, Pauline's scoliosis was under the treatment of JIP “Jippy” James, then a world-renowned scoliosis expert. He advised her never to have surgery for her scoliosis, but gave her exercises and routines to help her manage. She does well to this day, except of course, now as with all of us, there is some deterioration due to aging.

She shared a few of the exercises that have helped her. “It is important to keep things even (balanced) if possible,” she said. The stronger, less affected side tends to get overused while we let it work for the weaker side. We have to put some effort into strengthening the weaker side, especially if we see the stronger side losing ground. The easiest exercise is a kind of shrugging motion with one shoulder – pulling it up and toward the back, around and back down.

Over time scoliosis can get worse after having stabilized. Pauline recommends putting something behind your back to help sit you up straight when sitting in a chair. You have to sit up or sit back at a slight obtuse angle – not forward or slouched. The tendency to sit a bit bent over also adds to indigestion. Sue is noticing that her strong arm is now having more spasms, pain, and weakness as her scoliosis and back weakness increases. She's going to give her “good arm” a little rest for a few

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days.

Our regulars Joe and Marilyn Grande were much missed, and we send good wishes and “get well soon” to Joe, who had several serious health issues over the last two months.

May 2012 be one of improved health and full of blessings.

Judy

___The next Riverside PPSG meeting:___

February 18

Riverside PPSG Meetings: third Saturday of even # months at 11 AM. - at the home of Bryan & Judy Mahoney, 3465 Ramona Drive, Riverside CA. **Lunch provided.**

For more info. contact: Judy at (951)788-9310 or email PPSRiverside@aol.com

Big Bear PPS Group

For information contact Marsha Hart at (909) 878-3092 or Email healthwithhart@charter.net

Polio Survivors Plus

Next meetings:_____

CALL FOR INFO

Meetings are held at Laguna Woods Village, 23822 Avenida Sevilla, Laguna Woods, CA
For information and to RSVP for gate entrance permit, contact: Sue Lau at (714) 639-7497, or email Maliebchen@aol.com; or Gene Minder efminder1@cox.net (949) 830-9347

Victorville PPS Group

Julie Huftle has offered to attend meeting with her mom, Shirley Huftle, and send in reports to the newsletter.

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Thank you, Julie, for giving your time and effort for the good of High Desert polio survivors, and for supporting your mom in her time of need.

We look forward to hearing more from Julie in the future.

Julie writes:

The December meeting was held at the Hesperia Country Club. There were 18 members and guests. †The food was very good and the company was wonderful.

The next meeting will be held on Tuesday, January 10th. We will be meeting at the El Pescador Mexican restaurant in Victorville. The February meeting is expected to meet in Tuesday, February 14th at the Golden Gate Chinese restaurant in Victorville.

Next meetings: _____

January 10

February 14

Regular mtgs. Are on the second **Tuesday** of every month. Location varies!

For information, contact Vi @ (760) 947-2140

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Letters

Dear Rick,

Wishing you and your wife a beautiful holiday season filled with joy!

The PPS Manager continues to be outstanding. You are giving so much to so many of us. "Thank you" is totally inadequate.

Warmly,
Lois

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[Regarding MMJ: Part 1 in November 2011 issue.]

Hi Rick,

PPS MANAGER

Read it all the way through ...

I liked the fact that you noted that Sandy went with you to your marijuana appointment. It kept it all very aboveboard and added a dimension that gave it a family decision sort of approach to your wellness. All in all, EXTREMELY well written. That was amazing considering what a taboo subject any type of drugs can pose.

GREAT JOB, my friend!
Gladys

--

Rick - Thank you so much for the uplifting newsletter. It never fails to give me an emotional boost, as well as some new ideas for coping with our common challenges. I especially enjoyed your writing about your thoughts and experiences as you entered the post-polio chapter of your life. I recently shared the newsletter email address with the aunt of my physical therapist. She lives in New York, and had not been able to find much support (or understanding) for post-polio survivors in her area, so she was delighted to have access to the online newsletter. So, you see how far and wide your influence is spreading! Elesa T. Covina

--

What a great newsletter. Thanks so much for doing it. I get a lot out of it and like to warm helpful style.
Janet of Washington

--

Hi Rick,

I stayed up for the past hour and a half mesmerized with reading everything.

I'm beginning to realize and understand what hypoventilation has done and is doing to me. My fog memory, namely that CO₂ buildup, is a silent killer... but you have made it clear to me that I must not be complacent, anymore. That letter of yours will accompany me on my visit to my way too complacent lung doctor just after I return from the sleep symposium. That thing called motivation and my waking up to the fact that I continue to wake up at least three times a night, and that Gladys Swensrud swears that she wakes not once and uses your highly touted Resmed VPAP ST, the one you have convinced me to get... all is startling evidence, convincing me, to start an appeals process with my insurance companies. Today, my DME supply company, for the Resmed device, notified me to go after the insurance company, because they feel I have tried all the Respironics BiPAP machines, but yet the computer chip reports are showing I'm waking up for no good reason... thus something has to be done... like try your Resmed suggestion.

PPS MANAGER

Thanks for all of your support by correspondence... Manny.

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Hi Rick,

Once again, I enjoyed reading the newsletter. You are very good at making it interesting and informative, in every issue.

I fell [recently] because my polio leg collapsed. I didn't have my brace on and thought I'd take my little dog out for a quick walk. Big mistake! I fractured my humerus bone in my polio arm and broke my nose in two places. Why do I continue to think I can do things without my assisted devices?

Keep up the great outreach to we polios.

Hugs,
Judy

WANTED

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May two thousand and twelve be a great year for you

May you count more blessings than ever before

May you find peace and joy in all that you do

PPS MANAGER

And keep troubles away from your door

Thank you readers and supporters for another year of the PPS Manager Newsletter.

*Your humble servant,
Rick Van Der Linden*

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 and Ann Howell. Special thanks to Alverda Cambunga, Lois Jackman, Richard Conrad, Jean Cullinan, and Nona Atkins. Your contributions keep this thing alive.

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The PPS Manager is published every other month by R.E. "Rick" Van Der Linden and is presented as management ideas.

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PPS MANAGER

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