Founded in 1989
The Post-Polio Support Group of Orange County
Newsletter
15231 Marne Circle
Irvine CA 92604
www.ppsupportoc.org
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These Best Laid Plans ...

As like many other readers of our newsletter, I have been in the past few years, enrolled in straight Medicare plus Part D for the drug coverage. And, like many others, with the exception of ONE YEAR and only one year, each year whatever plan in which I was enrolled sent out a notice at some point saying that plan would self-destruct at the end of the calendar year. When I received that notice in October of 2010, I began to review the options listed in the 2010 Medicare book in hopes that SOME of those plans would be returning as options for 2011, maybe not exactly the same, but similar. So I began calling the enrollment offices of plans that I thought might serve my needs. They all told me, of course, that options would probably change but my contention was that, since they had to provide Medicare with the 2011 information for the Open period to begin within a month, they had to have SOME idea as to the benefits and formularies that would be available and, for the most part, that supposition was accurate. This was especially true if they had underwriting specialists or agents to whom they referred enrollment inquiries. So began my investigations for 2011 enrollment options. When I finally got the booklet from Social Security, I realized JUST how limited my options were should I decide to go with any thing other than straight Medicare plus Part D. In fact, my options were limited (in Orange County) to two Blue Cross plans, one with and one without Drug coverage. Since the bulk of my annual medical costs are eaten up by Prescription drugs, I really had straight Medicare plus a Plan D option or the Blue Cross plan unless I wished to jettison the 35+ year relationship with my primary care giver and switch to an HMO. To me, that was NOT an option. My physician has spent a great deal of time and energy investigating Post Polio, effective drugs and treatments and conferring with colleagues who either HAVE post polio or treat significant numbers of PPS-ers. Continued on Page 2

Inside this Issue

Possible questions for Dr. Rubinstein:

- Is it possible to develop new weakness in a limb determined to be unaffected at the time of the polio attack on us?
- Could the inflammatory response to polio virus particulates in a survivors' spinal fluid (the cause of PPS) impede healing and strengthening after surgery?
- What are the criteria in evaluating the desirability of upper body surgery on a polio survivor with PPS?

Come on Saturday March 12th 2-4pm

See Page 8 for map

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So, as you can see, my choices were few. I first called SS to request assistance in finding the plan or Plans that covered, if not all, the bulk of my prescriptions. No plan covered them all. Even after three calls, after talking to three separate people, strangely enough, there were discrepancies in what the suggested plans truly DID cover. That made me VERY nervous. If we lay folks cannot depend on the "experts" to provide us with accurate information, we are all in deep trouble. I can tell you it was very disturbing to me. I used to be very actively involved in creating and administrating health programs for large organizations in both the public and private sectors and am far more sophisticated about such things than the average lay person and yet I, too, was getting incorrect information on which to base my decision. I can only imagine how helpless those averagely knowledgeable folks feel in trying to maneuver this minefield on their own.

Finally, after several calls to several Part D providers, the calls to Social Security I had already made, I decided to try, for the first time, a Medicare Advantage plan through Blue Cross. Now keep in mind I indicated that BC had ONLY one plan with coverage for drugs and, per their requirements, I could not get a Part D IN ADDITION to the Advantage Plan that had no drug coverage, I still thought that I would try the BC plan this year even if it only lasted the one year typical of all the other Part D plans I had taken in the past so I called BC's enrollment department on November 15 to begin the process. The department I had been working with gave me specific instructions about what to say to THEIR enrollment person so I would be enrolled in the proper plan which is the information I offered when I spoke with the young woman who enrolled me.

Thinking I had gotten through the process quickly enough to get my cards and enrollment information and formulary on a timely basis, I felt pretty good about the whole thing. And I did get my cards, a book showing all my physicians were members, and the formulary listed that all the drugs they said they would cover were listed as covered so I felt pretty set. That was by mid-December.

After the 1st of January 2011, when I went into Costco where my prescriptions are on file, I was astounded to learn that although one RX was covered, the other was not, and further the one that they said was covered was ONLY covered for a 30 day supply and I had, per doctors order renewed at 50 days (100 pills) so they were not going to pay for either one.

I went home but the office and people with whom I had been communicating at Blue Cross had left for the day but the young lady I spoke to was very sincere in her efforts to help me. She just could not figure out why the second Rx was NOT covered as per the record of info transmitted to the pharmacy when it clearly showed in the formulary that it was. So, up the chain we went. I must say, I am exceedingly fortunate to find that Blue Cross for whatever faults they may have, do a tremendously thorough job of documenting all interactions with both members and prospective members and they had records of all my calls, all the drugs I discussed, who I spoke to and the information they provided. After discussing my situation with the supervisor in that department and her counterpart in enrollment, it came to light that the young woman who actually enrolled me, put me into the none drug plan. Therefore, no drug coverage on any medication at any number. I was stunned.

As I mentioned, though, their tracking made it very clear that my intent had ALWAYS been to enroll in the plan which provided drug coverage so they stated they would implement the process to dis-enroll me from the wrong plan and enroll me into the correct plan. This is not as simple as one would hope. They must gain approval from Social Security to do this, both for the dis-enrollment and for the proper enrollment as we had how gone beyond the Open Enrollment period which ended on Dec. 31.

What I have no yet discovered, and which makes little or no sense, though, is why they were willing to cover one prescription if I had taken ONLY a 30 day supply, why they sent me formularies for a plan that had no drug coverage and how the enrollment person had managed to enroll me in the wrong plan while looking at the same information tat which the rest of her colleagues wee looking. Probably no one will ever know those answers.

I have now been enrolled in the correct plan, gotten new cards, another book of listed member doctors, and an additional formulary. The new formulary does not state, however, that there is a 30 pill max on a drug that I have been prescriber to take twice daily and they won't give me enough for that prescribed 30 days if I take as directed. I am also having to fight with my physicians over billings that, to date, went swimmingly under straight Medicare but because of the mix up over coverage and plans during the month of January, they are disallowing all claims in either plan from doctors I saw during that period.

At some future date I am sure this will be resolved, hopefully before I croak.

As I said to begin with, the best laid plans (per Robbie Burns) "aft gage agley". ###

J.Renison, co-editor

Affordable Healthcare Act, Round TWO

With the finding by Florida judge Roger Vinson that mandatory health enrollment beginning in 2014 is unconstitutional has bred new life into the Tea Partiers' stance that it should be repealed. While Judge Vinson did NOT suspend the law but stated that the federal government should abide by his ruling which would potentially complicate its implementation in some states, more especially those who have filed suit thus far to nullify its implementation in their various states.

Those 26 states in the lawsuit contend that the statute is DEAD in its entirety, per David B. Rivkin Jr. The Obama government, of course, disputes that interpretation.

For those lay people like me who see some significant parallels between Social Security requirements, taxation, etc. it is difficult to understand how and why the federal government is able to do one but not the other. But I am certain that things will become clear over time, one way or the other. I believe we can all safely assume that this legislation will wend its way to the Supreme Court which will make the final and binding decision The government is asserting that the Commerce Clause of the Constitution provides the basis for the universal enrollment mandate. As parts of the law have already taken effect and for many Americans benefits such as drug discounts for seniors, tax credits for small businesses, elimination of the ban of preexisting conditions for enrollment and carrying dependents to age 26, the genie is already out of the bottle. People who benefit from those provisions will be loathe to relinquish them. Reading the results of polls is certainly not particularly enlightening in that they tend to contradict each other. If you want to support one position or

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another, just keep reading the literature. You can find information that will support any view, never fear. However, for those who are trying to keep an open mind and figure out what **IS** the will of the majority and what is constitutional, your guess is as good as the next one. I can assure you, I would not wish to put money on any one viewpoint over another.

The intent of the universal mandate, of course, is to spread the risk more broadly across the populace, and thereby control and moderate premiums so that additional benefits could be covered, especially the issue of preexisting condition coverage. If the universal mandate is set aside, people who are healthy will put off enrolling until such time as they get sick which means higher costs for those in the plans. If we are concerned about the uninsured going to high priced ERs and the like for coverage as they do not carry insurance to cover their needs, you can only imagine the exponential increase in the numbers who will take this option in the future. There are rules that state hospitals MUST take those who enter their portals for service whether or not they are able to pay. But, be assured, SOMEONE will pay for that care.

It is, however, this provision on which the Republican politicians have hung their efforts to repeal the entire law. I am rather curious to know WHO they believe will pay for all those uninsured folks who receive care. The Easter bunny? Santa Claus? My supposition, however uninformed, is that it will be the average taxpayer, and those who are insured. I could, of course be wrong but somehow rather doubt it. Had this not been the case thus far, our insurance premiums would not just keep going UP UP UP ...

It will be interesting to see how Round Two resolves. ### *J.Renison, co-editor*

TWO CURES FOR A SICK SYSTEM

By Ronald Brownstein
(LA Times 12-17-10)

The war between the parties over healthcare is deepening and widening. And the outcome could reshape the healthcare system as profoundly as the sweeping reform legislation that President Obama signed last spring.

The central points of contention in the healthcare clash remain the law's requirement that almost all American's purchase health insurance and the subsidies that would help them pay for it. This week's decision from a Republican appointed US District Court judge in Virginia to overturn that individual mandate virtually assures that the battle will rage until the Supreme Court settles it, probably years from now.

But while the conflict over expanding access seems likely to rule the headlines, the flurry of proposals for taming Washington's long-term debt is crystallizing an equally momentous argument over controlling costs, the nation's other major healthcare priority. Without restraining healthcare spending, Washington simply has no chance of balancing its books.

As the debate over the long term debt heats up, it is clarifying the parties contrasting visions for controlling healthcare spending. The core difference is the Republicans hope to control costs primarily by changing the financial incentives for patients, while Democrats place the most chips on changing incentives for providers.

The essence of the Republican strategy is that Americans will spend less on healthcare if they must pay for more of it themselves. GOP proposals inherently argue that Americans use too much healthcare because

overly inclusive health insurance has excessively insulated them from these costs. That conviction drives the Republican support for eliminating the tax subsidy for employer provided health insurance. It also inspires the proposal from a leading GOP thinker, Rep. Paul Ryan of Wisconsin, to convert Medicare into a voucher system that seniors would use to purchase private insurance. Over time, each of those approaches would probably drive more Americans to buy insurance that covers catastrophic expenses only, while encouraging them to pay out of pocket for routine health care costs

Democrats don't completely dismiss those demand-side proposals. But, mostly, they argue that relying primarily on patients to control costs is unfair and ineffective: Unfair because it shifts the financial risk from the government to individuals and widens the gap in access to healthcare between rich and poor; ineffective because the biggest factor driving costs isn't unnecessary doctor visits but unavoidable and very expensive, care for chronic conditions that catastrophic insurance would still cover. The way to control these costs, Democrats argue, is through supply-side policies that financially nudge doctors, hospitals and other providers to better coordinate treatments of the chronically ill and that generally link their compensation less to the volume of care than to its quality. The two big deficit reduction commissions that recently dropped tomes on Washington reflect this divide. The Obama appointed group chaired by Republican Alan Simpson and Democrat Erskine Bowles focused mostly on providers by accelerating the healthcare law's payment and delivery system reforms. The panel chaired by former GOP Sen. Oete Domenici and Democratic former OMB Director Alice Rivlin proposed converting Medicare into a voucher program nd eliminating tax breaks for employer provided health insurance. (**Disclosure:** My wife works for the Bipartisan Policy Center, which sponsored the Domenici-Rivlin commission).

Simpson and Bowles didn't embrace any of those ideas, but they didn't rule them out either, especially if the rise in healthcare costs doesn't slow. Domenici and Rivlin praised the healthcare bill's provider reforms. In effect, both groups acknowledged that neither the patient level nor the provider lever alone can control surging healthcare costs.

Yet the overlap extends only so far. As the healthcare debate smolders, nothing will separate the parties more importantly than whether they ask patients or providers to shoulder the principal burden of breaking the feverish rise in healthcare spending. ###

Professional Education in PPS

We are working with Kaiser Permanente on a plan to conduct professionally accredited Continuing Education in 2012 for physicians and therapists in the diagnosis and care of PPS. The information collected in our Survey has been shared and planning, registration and publicity programs are being studied. Our key responsibility will be to persuade each of our doctors and therapists to participate in this day of learning and training. We are looking to make Southern California the best region in the USA for PPS care.

In the meantime be sure to **consult the list of caregivers** rated positive in the care polio survivors found on the Providers ***link*** of **www.ppsupportoc.org.** Those on the list had at least one positive rating and no negative rating.

Stay tuned for information and schedules as they develop.

Post-Polio Thoughts

Nancy Baldwin Carter, BA, M Ed Psych, Omaha, Nebraska, (n.carter@cox.net)

Opportunity Knocks

Have you heard? Rotary International (yes, the same wonderful service organization that has already contributed over $600 million to polio eradication worldwide) is taking a look at the late effects of polio! Much of the September issue of their magazine, The Rotarian, is devoted to post-polio. Take a look!

That's you and me they're talking about—and some of them, too. A certain number of Rotarians are polio survivors, remember. All of us are hopeful that this glimpse into the critical needs of polio survivors in developed countries, such as the United States, will give us the boost we've been longing for.

More good luck: Some Rotarians are also doctors. Perhaps more than anyone else, they understand the need for post-polio research to unlock the puzzles of this condition; they realize the importance of training knowledgeable health professionals.

Their magazine sets the scene perfectly for PHI's current WE'RE STILL HERE! project. It's this easy: First, Rotarians read all about the late effects of polio in The Rotarian.

Then, polio survivors arrange to address members at a Rotary meeting. We give our personal touch to the story by mentioning a little bit about our own post-polio journey. They can learn from our experiences, and we can paint a thoughtfully beneficial picture for them. We thank Rotary for all they've done so far and congratulate them for deciding to continue down the post-polio path.

We describe what having more doctors and therapists trained in post-polio issues would mean in our lives, personally, and to others like us. We mention the need many have for equipment, like braces and wheelchairs and chair lifts and other assistive devices. We emphasize the worth of research in finding a reliable diagnosis, with the further hope of then discovering dependable methods of treatment for post-polio conditions.

We answer questions in a short Q&A session, if Rotarians want this, and invite them to take a stroll through the PHI website (www.post-polio.org), with special attention to the Advocacy tab.

And finally, of course, we have the donation form for groups or individuals who care to contribute. For decades, PHI has played a vital role in effectively reaching out, dedicated to educating health professionals and polio survivors as well, always serving those in need. Here's an opportunity to ensure the future through PHI's continued research projects, dissemination of information, advocacy, and support.

Voila! Rotarians get new ideas through this collaboration—they see how they can continue to improve the lives of many polio survivors, at home and abroad, struggling with a myriad of post-polio problems.

Those of us participating can be sure our words are heard when we present our talks to a group of Rotarians. This is an interested audience. They've been working in this field for fifteen years. If anyone is caught up in the story we have to tell, Rotarians are.

It's up to us. This is the time and the place. What could be easier? We have only to dash to the phone and book a speaking date with a local Rotary meeting. They're waiting to hear from us. They all want the message behind WE'RE STILL HERE!

That's the white pages. Under Rotary.

Nancy Baldwin Carter, B.A, M.Ed.Psych, from Omaha, Nebraska, is a polio survivor, a writer, and is founder and former director of Nebraska Polio Survivors Association.

Source: Post-Polio Health International (www.post-polio.org)

2 ways to help your support group

• Agree to have the Orange County Newsletter sent to you by email. THIS IS VOLUNTARY. To do this, please send an email to editorBaldwin@ppsupportoc.org.

• Mail a small contribution to **Polio Survivors Association** and write "Orange County" in the memo section. Please **mail checks to** Priscilla Hiers, Treasurer PPSG of OC, 18552 Cork Street, Fountain Valley, CA, 92708.

How to contact Rancho Support Group:

The Rancho Los Amigos Post-Polio Newsletter is published as a joint venture with the Polio Survivors Association.

For additional information please call Richard at **562-862-4508**

Or email us:
Rancho PPSG@hotmail.com

Websites
www.RanchoPPSG.com
www.ppsupportoc.org

How to contact OC Support Group:

Call us for information:
Marte Fuller **562-697-0507**
Marilyn Andrews **714-839-3121**

Newsletter co-editors:
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renison@cox.net

Agenda ideas for PPSG of OC?
Please call Aleta at 949-559-7102 or email Priscilla at prisofoc@aol.com

Special thanks to the following donors: Barbara Smith, Patricia O'Neill, Marlene Baer, Alliene Spence, Nancy Norwood, Floyd Powley . We mention donations but not the amount, as all donations make our support group possible. Please write checks to **Polio Survivors Association** and write "Orange County" in the memo section. Please **mail checks to** Priscilla Hiers, Treasurer PPSG of OC, 18552 Cork Street, Fountain Valley, CA, 92708

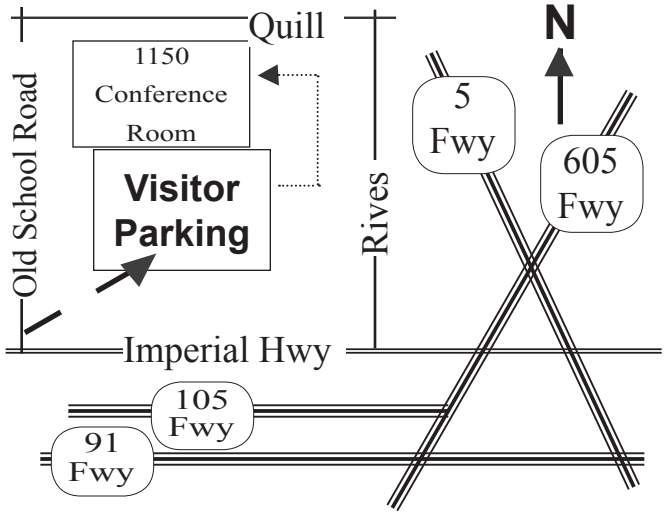
Rancho Los Amigos Meeting

Saturday March 26
2 PM - 4 PM
Making Life Easier and Safer:
A discussion of our individual histories of adaptation and problem solving.
Think about your first piece of adaptive equipment.
What is your newest home adaptation?

Future Rancho SG Meetings

APRIL MEETING
TO BE DETERMINED

SUNDAY MAY 22ND
JOINT MEETING WITH THE ORANGE COUNTY SUPPORT GROUP



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

Orange County Meeting

Saturday March 12
2PM - 4PM

Dr. Rubinstein
on **Upper Body Orthopedics**

VILLA PARK CITY COUNCIL CHAMBERS
See Map Below

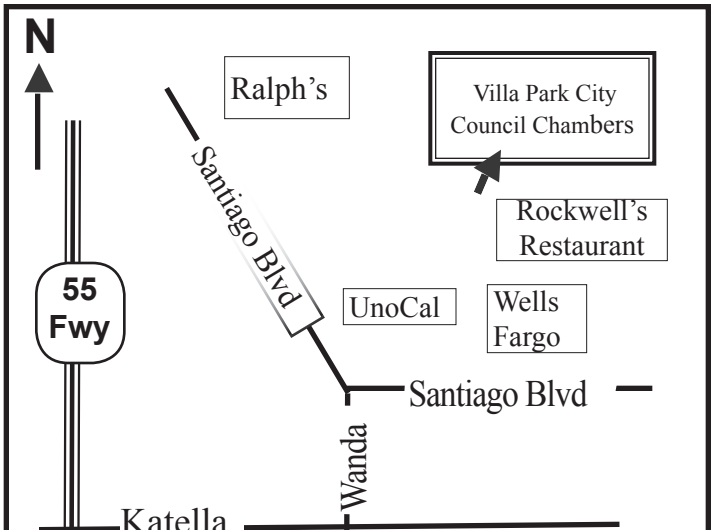
Future PPSG of OC Meetings

Saturday April 9th 2-4 pm
Movie: "The Final Inch"
***Polio Eradication*.**

SUNDAY May 22nd 2-4 pm

Dr Susan Perlman, Director of the Post-Polio Clinic at UCLA, will speak on current **PPS RESEARCH**

Saturday June 11th 2-4 pm
VAN CONVERSIONS



We meet **2nd Saturdays** 2 - 4 PM
Villa Park Council Chambers
17855 Santiago Blvd. Villa Park
May meeting usually on a SUNDAY
December at Rancho in Downey