

Newsletter

Post-Polio Support Group of Orange County

Founded 1989

WEBSITE: ppssupportoc.org

NOV. 2016

Coming Events:

HICAP ANNUAL UPDATE MEETING

On Saturday, November 12, at 2 PM we will be given the ANNUAL update on Medicare insurance plans for 2017. It is strongly suggested that you give yourself more than usual time for parking as Rockwell's is holding a Holiday Faire between their restaurant and the Council Chambers. While the ramp will be available it will be very crowded and may be difficult to maneuver. If you need assistance, call Baldwin on his cel (949) 981-2605 and he will help you getting in or out. The choices on plans are limited this year and the Part D formularies as well.

My 2017 Challenge

This year, I suspect, was a challenge for many of us trying to find an insurance company covering both our doctors and all of our medications. I can assure you, this was the case for me. When checking with Medicare to verify whether or not I should stay with my current plan (Silver Script) or go elsewhere, I was dismayed to find that they will not cover 5 of the 9 Meds I need next year. In fact, none of the Part D Plans would cover the majority of the medications needed to treat the chronic conditions associated with my Post Polio Syndrome. So the search was on. Unless you are part of an HMO next year, your choices are extremely limited. Having been with my primary care physician for 42 years, changing was my least desired option. Fortunately for me, he is part of the St. Joseph group of physicians and physician groups and Scan contracts with them. So, I had one possible choice that would cover at least two of my current four health team members. The other two are not.

Changing doctors who have treated you for years and in whom you have confidence, have gone through significant health crises and their resolution, is no small matter. As a PPS-er, we tend to have health crises somewhat regularly as we age. I hit the big 7-5 last month and health crises for me are now rather regular events. In order

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to find a new doctor, the investigative process is rather arduous and time consuming and this does not begin to address the issues of confidence and rapport. I have had, for short periods of time, several physicians with whom that rapport never developed and so I left to find alternatives. In this healthcare environment, there were more times that the doctors I truly bonded with left ME. The group changed, the insurance changed, they moved their offices or some other administrative action occurred that forced me to find alternatives.

That is always a sad disconnect as building that rapport takes time and is a valuable interaction. The medical history that also develops is every bit as important as the emotional and professional interaction.

In my research this year I made an interesting discovery. One of the drugs listed in my 2016 formulary ceased being covered shortly after the beginning of the year. When it was denied at the pharmacy, the reason was given that it wasn't in the formulary. According to Medicare, the insurance company is to send notice to the members when it is dropping drug coverage but that didn't happen. Imagine my surprise, then, to see that same drug listed in the NEW formulary for 2017. When I asked how the company can print inaccurate information, Medicare informed me that accuracy was not their concern. I asked where to complain about information that was misleading people to sign up only to find out the coverage they THINK they have is not the coverage they will get. The answer is that you must contact the insurance company who has printed the erroneous information to complain and seek redress. Medicare does not have any mechanism or obligation to enforce the provisions of the Affordable Care Act. It appears to be a self regulated function and "woe" be to the person who discovers such discrepancies. Need help? You are out of luck. If you are like me, each of those "discrepancies" translate to many hundreds of dollars per month. I take/use 9 separate medications daily. Of those 9, only three are generic. I have drug sensitivities to many drugs and generics tend not to be effective for me. If anyone tries to tell you that generics are the equal of the original patented drug formulation, I have a bridge that you might be interested in buying. Each drug formulation can be changed in any number of ways, fillers, amount of active ingredients, etc. They are often not the same at all. I use Ultram for pain control. When trying to find a generic of that medication, I tried twelve different generic Meds and found only one which did, in fact, reduce the pain to the same level that Ultram does. That generic is made by Sandoz Pharmaceuticals, based in Europe. I had to call them directly to find the name(s) of their US distributors (Walgreens and CVS). However, when calling around my geographic area to the various Walgreens and CVS pharmacies, not a one got their generics from Sandoz nor would they even TRY to obtain the drug for me. You, as a customer, take whatever generic option that the drugstore chooses (and that is based on price). So in reality, you have no ability to influence which generic drug version is available to you. If I want an effective medication, I am required to take the name brand drug, regardless of price. In this case the Ultram is several hundred dollars per month for a 30 day supply. Multiply this experience by 5 additional drugs and you can see how easily it becomes for people to have to choose food or housing costs over the drugs that keep them alive.

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I remember how grateful I was when I became eligible for Medicare and equally grateful when Part D was enacted in that each provided some financial relief from my drug cost burdens. It has been sad to see with every year those costs go up on every drug prescribed, fewer and fewer options for coverage, and significant erosion in the benefits to be found in every one of those programs that were once a significant help to me. This may be the year, however, that causes me to make those food or drug choices that so many others have had to make.

I am not adverse to companies making a profit for their investors. I own mutual funds. It is those profits that have supported the purchase of my drugs to date. But every year, without fail, the price for the same drugs I have been taking for years have escalated. Congress has called drug executives like Martin Shkrelli of Turing, the CEO of Malan, the maker of the Epipen, the CEO of Valeant and Gilead, all because of huge and unsubstantiated increases in drug pricing all to no avail. These price increases are not, as stated by the pharmaceutical companies, because of research costs. The research is long over and the costs covered by drug purchases of the past. The cost of doing business. Maybe? Maybe not so much. From what I have read and seen, it appears that simple profits, motivated by pharmaceutical company greed is the main motivating impetus.

In too many cases, people do without. They have no choice and simply cannot pay for their medications. In many of those cases where folks do without, it is a difference of life or death. Many times people DO die. There ought to be another option for the "richest country in the world".

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CALIFORNIA IS GROUND ZERO IN THE FIGHT TO STOP DRUG PRICE GOUGING

Prescription drug prices in the US are the highest in the world --- by far. Californians on Nov. 8 have a chance to stand up to the pharmaceutical industry's greed and spark a national movement to end this price-gouging. As of now, no laws prevent drug companies from doubling or tripling or adding even greater multiples to their prices. So they just do it. The more recent flagrant example is the emergency allergy injection, the EpiPen. It's maker, Mylan, jacked up the price of this 40 year old medication by 461% between 2007 and 2015. During that same period, compensation for Mylan's CEO rose 671%. And that's just one company and one drug.

Proposition 61, California Drug Price Relief Act, would bar the state from paying more than the US Dept. of Veteran's Affairs does for the same drugs. That would include medicine purchased for state employees and retirees, university students, prison inmates, uninsured people with HIV/AIDS and Californians covered by public insurance program Medi-Cal.

The VA pays an estimated 24% less for drugs than most government agencies and about 40% less than Medicare Part D. Those are significant savings. In California, Proposition 61 would make drugs more affordable and accessible for about 6 million people.

The soaring cost of medicines a major health crisis nationwide. One out of five Americans age 19 to 64 cannot afford their prescriptions. Hundreds of thousands of seniors cut their pills in half to stretch one month's prescription. Into two. Many of those patients will get sicker and some will die. Meanwhile, the five largest drug companies made more than \$50 BILLION in profits last year. The top 10 CEOs in the industry received a total of more than \$327 million in compensation.

How have pharma companies gotten away with such avarice?? They currently have 1,266 lobbyists on their payrolls in Washington, DC, and 118 fighting for their priorities in Sacramento. They've made hundreds of millions in campaign contributions to politicians. And just this year, massive pharma lobbying efforts killed two bill in the heavily Democratic California Legislature that would have made modest steps toward drug-pricing transparency.

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Now, drug makers are using their cash and clout to try to defeat Proposition 61. Incredibly, the measure's opponents are prepared to spend up to \$100 million in California to make sure that Americans continue paying the highest drug prices in the world. Why? A major pharmaceutical industry publication has called Proposition 61 "ground zero" in the fight against high drug prices, and warned drug company executives that "adoption of VA pricing by the state of California would be a 'pricing disaster' for the the entire US drug industry".

Their TV ads have mostly featured veterans who lament that if Proposition 61 passes the drug industry will raise the prices it charges the VA. NOT TRUE!!!

As the former chairman of the Senate Veteran's Affairs Committee, I would never support a measure that harms our veterans. Pharmaceutical companies cannot unilaterally raise the price of drugs it sells to the VA. The most that the VA pays for a drug is either the best commercial price minus discounts and rebates, or the average price paid by pharmacies minus a large discount, whichever is lower. Those price caps are set in law. The VA also receives additional discounts if drug prices rise faster than general inflation. In other words, drug companies cannot just jack up the cost of drugs it sells to the VA.

In addition, veterans' drug co-payments are fixed and do not rise even if drug prices go up. It is also important to note that veterans being treated for any condition related to their military service pay no out-of-pocket costs whatsoever for prescription drugs.

The drug industry also argues that less than 20% of Californians will benefit from Proposition 61. In fact, the measure will provide relief to all Californians whose tax dollars pay for the drugs used to treat many Medi-Cal recipients and state employees. Taxpayers would save an estimated \$1 billion a year.

It's unacceptable that the exact drugs that we buy in our country are sold in Canada, Britain and other countries for a FRACTION of the price. My urgent message is to vote YES on Proposition 61 to make medicine more affordable in California and send a signal to Washington that the whole nation's prescription drug policies need an overhaul.

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Article by Senator Bernie Sanders (I-VT)

Reprinted from Los Angeles Times, October, 2016

WHY WE PAY TWICE FOR DRUG DEVELOPMENT

Most Drugs Originate Thanks to Public Funds, not private R & D.

When Martin Shkreli, of Turing Pharmaceuticals raised the price for Daprim by 5,455%, he put drug pricing on the agenda for the 2016 presidential candidates. Bernie Sanders is reported to have rejected Shkreli's campaign donation, Hilary Clinton came out with a plan to tackle spiraling costs and even Donald Trump called Shkreli a spoiled brat.

Everyone knows that Americans pay high prices for drugs. But the taxpayer not only shells out at the pharmacy but often plays a critical role in the initial funding of these drugs in the first place. In other words, THE PUBLIC PAYS TWICE.

Although the pharmaceutical industry justifies routine overcharging by pointing to the huge and uncertain costs of research, the truth is the government historically took and continues to take, the greatest risks.

Since its founding in 1936, the National Institutes of Health has invested close to \$900 BILLION in the basic and applied research formed by both the pharmaceutical and biotechnical sectors, with the private companies only seriously getting into the biotech game in the 1980s. THE NIH continues to spend about \$30 billion a year on such research.

Big Pharma, while of course contributing to innovation has increasingly recommitted itself from the high risk side of research and development. often letting small biotech companies and the NIH do most of the hard work. Indeed, roughly 75% of so-called new molecular entities with priority rating (the most innovative drugs) trace their existence to NIH funding while companies spend more on "me, too" drugs — slight variations of existing ones.

But if big Pharma is not committed to research, how and why do they justify their astronomical prices for their formularies? First, it is well known that Big Pharma spend well more on marketing than R&D. Less well known is how much it spends on making its shareholders and executives rich.

Maybe it is time for a reevaluation of this distribution of profits. It is a thought.



**Rancho Los Amigos
Meeting
Saturday, Dec. 3,
2016
Polio History**

Orange County Meeting

**Saturday, Nov. 12, 2016
2:00 - 4:00 PM**

H I C A P

!!!!Come Early!!!

Future PPSG of OC Meetings

SATURDAY, Dec 3, 2016

2-4 PM

Joint Mtg w/ Rancho at Rancho

Saturday, January 28, 2017

2:00 - 4:00 PM

DISASTER PREPAREDNESS

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

The Rancho Los Amigos Post-Polio Support Group publishes on even numbered months and the Post-Polio Support Group of Orange County publishes on the odd numbered months. We share the same mailing list, and all donations are shared equally. We mention donations but not the amount, as **all** donations make or support groups

How to contact support groups

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

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

Or email us:
Rancho PPSG@hotmail.com

Contact PPSG of OC for information:

Newsletter Editors

Janet Renison 949-951-8613
renison@lagunawoodsvillage.net

Baldwin Keenan 949-857-8828
abaldwinkeenan@gmail.com

Agenda ideas for PPSG of OC?

Please call Aleta at 949-559-7102 or email Priscilla at prisofoc@aol.com

WEBSITE: ppsupportoc.org

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**Orange County
Post-Polio Support Group
3454 A Bahia Blanca West
Laguna Woods CA 92653**

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

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