

## Continuing Education in PPS care for doctors, nurses, and therapists

by BALDWIN KEENAN  
 co-editor

Several months ago Joan Headley, of Post-Polio Health International, asked me to come up with some new ideas for **We're Still Here** that might be appropriate for participation by Rotary International.

Just that week I had listened to the chronic frustration of co-survivors in regards to their not getting care from polio trained caregivers. They had chosen Medicare Advantage HMOs, not for medical reasons but for economic security reasons. As I was thinking of ideas for Joan, it dawned on me that since the majority of So California polio survivors are not going to leave their HMOs, the solution is to train enough doctors in HMOs to take care of the polio population. All medical caregivers require Continuing Education. **CME** for physicians. **CNE** for Nurses and **CE** for Physical Therapists. We should be able, perhaps with the support of Rotary

**WE'RE  
 STILL  
 HERE**

### Inside this Issue

Train more PPS caregivers	Pgs 1-2
Questionnaire results	Pgs 2-3
Now to the hard work	Pg 4
Types of Health Care	Pg 5
Medicare options???	Pg 6
Richard Daggett's book	Pg 7
Contact & Meeting Info	Pg 7-8

International, to organize a day of PPS training for the professional caregivers of polio survivors.

Slightly over 40% of local readers of Southern California Polio support group newsletters have completed questionnaires identifying their health insurance company, doctor group, and the primary care and specialists who take care of their polio related and other illnesses.

The idea to launch this initiative is an idea many years in the making. Not long after I started coming to Orange County PPS meetings I was approved for Medicare Disability Insurance. Two years later I had to choose between straight Medicare or a Medicare Advantage HMO. Dan Holloway was the devoted husband to a dear, now departed, polio survivor, who befriended me in the early days when the realities of PPS overcame me. Dan urged me to just get on Medicare and not to even buy supplemental insurance. He told me that I would want to have easy access to doctors and physical therapists who had been trained in PPS. He explained that members of our group in HMOs had little success in getting to caregivers who knew about polio and post-polio. He stressed that **my health would be worth whatever extra it cost**. I am quite willing to drive 20 miles to a neurologist and an orthopedist along with a team of physical and occupational therapists who have years of experience caring for polio survivors. I pay 20% of what Medicare determines to be the cost of an office visit or medical procedure. Office visits cost me about \$15. Lab work is usually free. One big expense I was happy to pay was \$700, my portion of the \$3500 cost of a custom carbon fiber brace. It provides such

excellent support and walking thrust that I almost never use crutches anymore and my wheelchair is in storage. The orthotists who make state of the art braces have generally stopped making quality braces for patients who have HMO insurance. The HMO reimbursement is based on “off the shelf” braces. Polio legs and feet don’t usually come in those sizes. Dan Holloway gave me great advice.

The surveys indicates that **HMOs work well for some survivors** who have been quite successful in getting care from doctors in various HMO contracted medical groups. Some primary care as well as specialist physicians have made the effort to learn PPS. In many instances, Kaiser Permanente, an HMO, has given very good care to polio survivors. Also a few medical groups, as well as Kaiser, have absorbed the cost of sending survivors to Dr. Perlman or Dr. Shanfield, even though they are not members of their medical group. The great majority in our PPS support groups are in Medicare Advantage HMO and complaints

about how “impossible” it is to see doctors who knows about polio are common. Medicare Advantage HMOs draw 80% of their customers from Southern Florida and California. They have convinced seniors in these two states that it is worth trading away easy access to specialized medical care (such as for PPS) for the economic security that comes with managed care. Survivors make this decision seriously. PPS may not be our only serious health problem, and many medical groups contracted to HMOs and Kaiser have proven well suited to treat the complex medical problems of seniors. **Some survivors are willing to pay to see PPS specialists out-of-pocket and use their HMO for all their other care** -- getting the best of both worlds. Despite our survey showing that survivors on straight Medicare are more satisfied with their PPS care, it is obvious that most of the 38,000 polio survivors in So. California are going to stay with a Medicare Advantage HMO because of their very low out of pocket costs.

### Here is the questionnaire summary:

% of 230 surveys	Heath Care Organization	Remarks
32%	Straight Medicare or Medicare with supplement or a Medicare preferred Provider Organization (PPO)	<ul style="list-style-type: none"> <li>• Many <u>more</u> than expected in this category with 3/4 positive about PPS care</li> <li>• EVEN THOUGH THEY CAN GO TO ANY CAREGIVER WHO ACCEPTS MEDICARE, 1/4 IN THIS CATEGORY SAY THEY ARE NOT GETTING GOOD CARE FOR PPS.</li> <li>• Driving a long distance to get good care for PPS is common</li> </ul>
23%	Kaiser	<ul style="list-style-type: none"> <li>• 3/5 at least partially positive about their PPS care listing caregivers in all survey categories</li> <li>• 2/5 decidedly negative about PPS care</li> <li>• One referral to Rancho Los Amigos</li> </ul>
11%	Anthem Blue Cross Blue Shield 65+	<ul style="list-style-type: none"> <li>• 1/3 decidedly negative about PPS care</li> <li>• 2/3 at least partially positive about PPS care</li> <li>• Two referrals to Dr. Shanfield, Orthopedist</li> <li>• One referral to Dr. Perlman at UCLA, neurologist</li> <li>• One referral to Dr. Mosaffar at UCI, neurologist</li> </ul>

<b>% of 230 surveys</b>	<b>Health Care Organization</b>	<b>Remarks</b>
8%	AARP United Health Care Secure Horizons	<ul style="list-style-type: none"> <li>• 3/5 at least partially positive about their PPS care</li> <li>• 2/5 decidedly negative about PPS care</li> <li>• 1 is able to see Dr Shanfield</li> <li>• 2 are able to see Dr.Perlman</li> <li>• 5 are getting good Physical Therapy for PPS</li> </ul>
5%	Health Net	<ul style="list-style-type: none"> <li>• 2/3 at least partially positive about their PPS care</li> <li>• 1/3 decidedly negative about PPS care</li> <li>• 1 referred to Dr. Eberly</li> </ul>
5%	Scan	<ul style="list-style-type: none"> <li>• Half at least partially positive about their PPS care</li> <li>• Half decidedly negative about PPS cae</li> <li>• 2 referred to Dr. Shanfield</li> <li>• 2 have excellent PT for PPS</li> </ul>
3%	Aetna	<ul style="list-style-type: none"> <li>• 1/2 at least partially positive about their PPS care</li> <li>• 2/3 decidedly negative about PPS care</li> <li>• 2 have good PT for PPS</li> </ul>
2%	Inter Valley Health	<ul style="list-style-type: none"> <li>• 3/4 at least partially positive about their PPS care</li> <li>• 1/4 decidedly negative about PPS care</li> <li>• 2 have good Pulmonologist for PPS</li> <li>• 1 has good PT for PPS</li> </ul>
1%	Cigna	<ul style="list-style-type: none"> <li>• All at least partially positive about their PPS care</li> <li>• 2 seeing Dr. Shanfield</li> <li>• 1 positive about Pulmonologist for PPS</li> </ul>
1%	Pacific Care	<ul style="list-style-type: none"> <li>• 2/3 at least partially positive about their PPS care</li> <li>• 1/3 decidedly negative about PPS care</li> </ul>
5%	<b>Various</b> <i>Including</i> FirstHealth MD Care Ventura County HMO VA/TriCare CareFirst	<ul style="list-style-type: none"> <li>• 3/5 at least partially positive about their PPS care</li> <li>• 2/5 decidedly negative about PPS care</li> <li>• 2 positive about their Pulmonologist for PPS</li> <li>• 3 positive about PT for PPS</li> </ul>
4%	MediCal CalOptima in OC	<ul style="list-style-type: none"> <li>• 2/5 at least partially positive about their PPS care</li> <li>• 3/5 decidedly negative about PPS care</li> <li>• One referred to Dr Shanfield</li> </ul>
.5%	No Insurance	Negative about care for PPS  (These survivors might consider applying for Medicare)

## Now for the difficult work . . .

We had expected that we could limit our focus to the HMOs most popular with polio survivors. However 8% of survey respondents say that they are not getting care from polio trained doctors and therapists and yet they are on straight Medicare. Possibly long drives are difficult. It is clear that we need to ensure that we approach doctors, nurses, and therapists from all regions of Southern California.

Kaiser Permanente plays a very strategic role in California health care. In Northern California it co-sponsored a symposium with local survivors on post-polio care. In San Diego, after considerable prodding by survivor Gladys and others, it established its Neuromuscular Respiratory Program, the protocols of which are now in place in the rest of Southern California. Kaiser's Christine Phan, a physical Medicine and Rehabilitation physician in Downey is in the Post-Polio Health International *Directory*. And we have been informed by Kaiser management that its primary care doctors are now routinely sending polio survivors to Kaiser neurologists for evaluation if indicated. These accomplishments plus the fact that Kaiser services every region of Southern California give us confidence that it may be willing to sponsor **Continuing Medical Education** in polio and Post-Polio Syndrome.

Given the spread in returned questionnaires, we also need to approach Blue Cross/Blue Shield, and AARP-United Health Care-Secure Horizons and ask them to be co-sponsors. Unlike Kaiser they do not employ doctors, but contract to medical groups. Most medical groups contract to multiple HMOs. If we are successful with the above mentioned HMOs, we should be able to promote the polio CME training to medical groups throughout Southern California. And of course we will contact each of the physicians and Medical Groups listed in our readers' survey responses.

Dr. Perlman a Neurologist who directs a polio clinic at UCLA has offered to help teach. We also plan to invite Dr.

Carol Vandernakker a Physical Medicine and Rehabilitation physician who directs the polio clinic at UC Davis, Christine Phan a Physical Medicine and Rehabilitation physician at Kaiser, the Post-Polio Clinic team from Rancho Los Amigos and Dr. Stewart Shanfield, an Orthopedist associated with St. Jude Medical Center.

### Please keep in mind:

- **Even if PPS-CME** is a smashing success we will not find a polio doctor in every medical group and near every survivor's home.
- **There will still be times** when a survivor who chooses to be in an HMO will have to put up a big fight to get care by a polio trained doctor or therapist or use some of the money saved by being in an HMO to pay for "outside" polio care.
- **1/3 of survivors** who responded to the survey choose straight Medicare, Medicare with a supplement, or a Medicare PPO. All three of these options make access to polio caregivers relatively easy. The month to month cost is more than an HMO. But when you factor in the years we live with PPS, are these survivors really paying more? Is it cheaper to see doctors who don't know polio and are not learning it? Is it cheaper to be instructed in exercise by a Physical Therapist who has never studied PPS? How long will one of us wear an off-the-shelf brace because that is all the HMO will pay for?
- **About half** of the survey respondents are getting some positive polio care with Kaiser and the other HMOs. Our website will soon list the providers that were named by survey respondents.
- **If** our Professional Development in care for PPS is successful there will be many more polio caregivers to add to our list.
- **Survivor** Astrid Gallegher attached this note: "Both my primary care doc and my Pulmologist sent me to other providers and specialists. In every case I think it is my responsibility to ensure that I get appropriate treatment."
- **Long ago VICTIMS**, let's make Southern California one place where we SURVIVORS take charge of our own health care!

## Basics of types of Health Care Available today

Medicare	Medicare + Supplement (Medigap)	Medicare Preferred Provider Organization	Medicare Advantage HMO	Private Insurance	Veterans Administration (VA)	MediCal CalOptima
<p>See any provider who accepts Medicare</p> <p>20% Co-pay of Medicare Allowed Charges</p> <p>Office visits cost us \$12 to \$20</p> <p>1st day in hospital may cost us \$1000</p> <p>We must buy a Medicare D plan for Prescription coverage</p>	<p>See any provider who accepts Medicare</p> <p>Very little or no co-pay</p> <p>1st day in hospital is usually covered</p> <p>We must buy a Medicare D plan for Prescription coverage</p> <p><b>See Medicare 2011 Book for cost of supplement</b></p> <p>Supplement covers much of what Medicare does not cover</p>	<p>See any provider who accepts Medicare</p> <p>Co-pay is less for a provider in the PPO network which is usually large. Can go out of network but the co-pay is more.</p> <p>We must buy a Medicare D plan for Prescription coverage</p> <p><b>See Medicare 2011 Book for cost and co-pays</b></p>	<p>Usually choose a specific provider group in a specific geographical area.</p> <p>Referral to specialist or to go outside of our group is done by primary care physician</p> <p>Lowest out of pocket costs which initially may save us money</p> <p>HMO value can only be evaluated individually on how well we are cared over time for with PPS and other conditions</p>	<p>Usually from employment.</p> <p>3 forms:</p> <p>Fee for service Provider bills and plan pays a percentage</p> <p>PPO. Co-pay is less for a provider in the PPO network which is usually large. Can go out of network but the co-pay is more</p> <p>HMO: Very similar to Medicare HMO</p> <p>Sometimes can be used as Medicare supplement</p>	<p>Many veterans use these services. it usually requires travelling some distance to a VA facility.</p> <p>Some veterans also have Medicare.</p> <p>Many career military have TriCare. It is comprehensive medical coverage which can be used in conjunction with Medicare.</p>	<p>Medicaid is a federal insurance program for people at very low incomes.</p> <p>California supplements Medicaid and in CA the program is called MediCal.</p> <p>The program in Orange County for MediCal HMO is called Cal Optima.</p> <p>Some seniors have a combined Medicare-MediCal insurance</p>

**Note on Kaiser Permanente, a different type of HMO:**

All other HMOs in Southern California use provider groups to service patients. Kaiser employs its physicians, nurses and therapists directly. It owns its hospitals.

# Questions about Medicare options?

## *California Health Advocates* have answers !

- California Health Advocates is the leading Medicare advocacy and education organization in California. It is a non-profit and receives financial support from a broad range of private and public organizations
- The premiere watchdog organization for Medicare in California: it conducts public policy research to support improved rights and protection of Medicare beneficiaries and their families through **HICAP** (the **H**ealth **I**nsurance **C**ounseling and **A**dvocacy **P**rogram)
  - Free, one-on-one Medicare counseling. Trained volunteer counselors answer your questions and help you understand your Medicare rights and benefits, including how to appeal denials of coverage; Medicare supplemental insurance (Medigap policies); Medicare Advantage plans; employee and retiree coverage; and long-term care insurance.
  - Legal help and representation at Medicare appeals or administrative hearings are also available.
  - HICAP provides free educational presentations on Medicare and related topics. Call your local HICAP to schedule a presentation or find out about one happening in your area.
  - HICAP counselors do not sell, recommend, or endorse any insurance product, agent, insurance company, or health plan.

<p><b>San Diego and Imperial Counties</b>                      3675 Ruffin Road Suite 315                      San Diego, Ca 92123                      tel: 858-565-8772 ext 203                      dweil@seniorlaw-sd.org                      M-F 8am -5pm</p>	<p><b>Orange County</b>                      www.coaoc.org                      1971 E 4th Street Suite 200                      Santa Ana CA 92705                      tel: 714-560-0424                      lroberts@coaoc.org M-F 8am - 4pm</p>
<p><b>Riverside and San Bernardino Counties</b>                      www.inlandagency.org/hicap.html                      1737 Atlantic Avenue Suite H-5                      Riverside CA 92507                      tel: 951-241-8723 ext 242                      scorbitt@inlandagency.org                      M-F 8:15am - 4:15pm</p>	<p><b>Los Angeles County</b>                      www.healthcarerights.org                      520 S Lafayette Park Suite 214                      Los Angeles CA 90057                      213-383-4519 800-824-0780                      sridson@healthcarerights.org                      M - F 8;30am - 4:30 - pm</p>
<p><b>Ventura County</b>                      646 County Square Drive Suite 100                      Ventura CA 93003                      805-477-7310                      Katharine.Raley@ventura.org                      M - F 8:30am - 4:30pm</p>	<p><b>Santa Barbara &amp; San Luis Obispo Counties</b>                      www.centralcoastseniors.org/hicap/                      528 South Broadway                      Santa Maria CA 93454                      tel:805-928-5663                      seniors@kcbx.net M - F 8am - 5pm</p>

## EDITOR NOTE:

*I read Richard's book in two sittings. I've read several polio survivor biographies. None like this. I was five and not too much hampered by a skinny hooked left leg when the virus hit Richard. He brought me inside the iron lung and he took over my vision so that I could see the disease and PPS like I never had before. My eyes had to adjust to his world.*

BALDWIN KEENAN



“Not Just Polio” recounts the remarkably full and enjoyable life of the author, Richard Lloyd Daggett. The narrative includes an honest and frank account of living with a significant disability. More than the story of a devastating illness, it also chronicles the life of a young person growing up in middle class America during the 1940s and 50s.

His ability to attain the equivalence of a college education, despite being physically unable to enter the classroom, is a subtle but strong display of his strength. The vision and determination which became evident during this long challenge were, without a doubt, significant elements which enhanced his effectiveness as an advocate to improve the welfare, comfort, and safety of severely disabled patients who lacked adequate resources.

AVAILABLE AT **Barnes & Noble** (by phone or online)  
Best price at **Amazon.com**

### 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**

**H&S PRINTING** does our newsletter at cost. Business is slow and Mark Hardy would like to talk with anyone who needs printing: **949-583-1632**

### How to contact OC Support Group

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**Agenda ideas for PPSG of OC?**

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WEBSITE: **PPSUPPORTOC.ORG**

WE WELCOME DONATIONS TO OUR SUPPORT GROUP WHICH MAKE THIS NEWSLETTER AND OUR MONTHLY PROGRAMS 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.

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### Rancho Los Amigos Meeting

**No Rancho meeting  
in November**

Note OC meeting

See you December 11th

### Orange County Meeting

**Sat. November 13**

2pm- 4pm

**Kathleen Shanfield**

Occupational Therapist

**Safety at home and other places**

In her presentation she will demonstrate useful gadgets

See map at bottom

### Future Rancho SG Meetings

**Sat. December 11**

2 pm - 4 pm

**Dr. Vance Eberly**

Rancho Orthopedic Report

At Rancho: 1150 Conference Room  
at Quill and Old School Road  
See map at bottom

### Future PPSG of OC Meeting

**Sat. December 11**

**Dr. Vance Eberly**

Rancho Orthopedic Report

In Downey. See map bottom left

**Sat. January 8th**

**Finger Food Potluck  
and rich conversation**

