

FROM THE EDITOR

Hi Fellow PPS Managers.

At the bottom of this column is the table of contents. Among the articles listed in the last issue was a story on the 2006 Medicare change. Within days of delivering 620 newsletters to the post office I got a call from John Hagee pointing out that the story was nowhere to be found.

John was worried because the company that supplied his bilevel breathing machine had sent him two letters causing him deep concern that Medicare would no longer pay for his breathing needs, leaving him out in the cold. I assured John that Medicare is trying to save money, not hurt him. I also promised to provide as much information as I can dig up on the subject. You'll find the basic information about the Medicare change in this issue, and more about what you can do to take care of yourself in the May issue.

Also, a very interesting story from Rick Kneeshaw: Rick and others are taking part in a program at UCSD. Doctors want to know about PPS and other neurological disorders. Read "Donate your Body ..."

Have fun....Rick VDL

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IN THIS ISSUE:

Medicare Changes by Rick VDL

Donate Your Body...

by Rick Kneeshaw

The Way to Get Home Health Care

Letters and much more...

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Into the Ditch

By Rick Van Der Linden

About a year and a half ago I made the decision to streamline my breathing treatment by dropping my sluggish HMO and going to Medicare Direct. It was a decision I do not regret. I quickly got the much needed equipment without the long wait and hassle. And with the addition of Part D, the overall benefit of Medicare direct has been positive for me.

Then along came the Deficit Reduction Act of 2005.

Signed into law on February 8, 2006, Public Law No. 109-171 moved a lot of money around. One seemingly insignificant section – number 1501 – deals with Medicare and the "Transfer Of Title Of Certain DME To Patient After 13-Month Rental." It turns out they were talking about my ST machine. It seemed like a bad thing at first, but after studying it closely I find that it's not a problem. However, for those of you who followed my lead, (and particularly

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those of you who recently received a scary letter from your DME supplier) you may be feeling like you followed me into a ditch.

Well, I'm here to tow you out.

I've spent a great deal of time studying the Medicare change, what it means to us personally, how to adjust to it, what we need to know and do, and what our current and future options might be.

If this sounds like an apology, I can't apologize for the government wanting to economize on the money we put away for our retirement, as long as we get what we need, when we need it.

I'm convinced that we will be just fine as long as we continue to diligently look after ourselves.

As usual, it's up to us to take care of ourselves.

Terms and acronyms used in the following article:

Bilevel – A breathing assistance machine that delivers positive pressure to the lungs via a hose and mask (usually) over the nose. A lower pressure allows out-breath, a higher pressure aids in-breath.

ST or S/T – Spontaneous and Timed. A breathing machine that reacts to your input, but also breathes for you should you stop breathing.

Back-up rate – Same as Timed (above). Refers to the set minimum rate of breaths per minute.

HMO and PPO – Health Maintenance Organization and Preferred Physician Organization. They mean about the same thing. You or Medicare pays them a monthly premium to provide your health care. It's like health insurance. But, you may see only their chosen (capitated) doctors and service providers, or pay extra to see those outside the system. You may have to make co-payments for each service. You may not bill Medicare for anything.

Medicare Direct or Direct Medicare – You do not choose an HMO or PPO. You use doctors and services of your choice as long as they agree to bill Medicare. You, generally, pay 20% of Medicare approved fees unless you claim financial hardship, have MediCal (or similar state provided supplemental support), or buy a supplemental insurance policy.

DME – Durable Medical Equipment

CMS – Centers for Medicare and Medicaid Services, decision makers and communicators.

Most others are explained in the article.

Medicare Change Takes Full Effect

By RE Van Der Linden

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If you use a bilevel S/T ventilator, and Direct Medicare is your payment method, the new Medicare regulations will affect you. If you have an HMO or PPO or private insurance, there may be no immediate effect. However, Medicare guidelines have a way of filtering down through other systems, so it won't hurt to pay attention.

The following information is the result of hours of researching the Medicare guidelines and publications. Of particular help was one called FR Doc 06-798.doc (copies available upon request). I also interviewed three DME providers. Two out of three were very helpful.

Here's what happened:

In 2005 Medicare made some cost reduction changes scheduled to go into effect January 1, 2006.

After seven years of looking into the situation, CMS made the final decision regarding a vexing question: Why should an ST machine, not substantially different from a CPAP or S machine, be so much more expensive to maintain. The official statement entitled FR Doc 06-798.doc was issued on January 27, 2006 by The Department of Health and Human Services. The 20-page document outlines the history of Capped Rentals, explains the final ruling, and how, after discussion with dissenting DME providers, the final decision was made.

The new ruling (effective April 1, 2006) is expected to save taxpayers millions of dollars a year. A large portion of those savings will come from reduced payments to the small businesses that provide ST machines to those of us with neuromuscular breathing disorders.

Before 2006, noninvasive positive pressure breathing assistance machines were separated into two categories:

- 1) Simple machines without a backup rate (CPAP "C" and bilevel "S" machines) – Medicare classified as Capped Rentals.
- 2) Machines with a backup rate (we'll call them ST machines) such as the **ResMed VPAP III ST** and **Respironics BiPAP S/T**. – Classified as FSS or Frequent and Substantial Servicing.

Capped Rentals (CR):

CPAP and bilevel "S" machines were not considered full ventilators because they don't have the capability of timing breaths and therefore they can't entirely take over breathing for you. Those machines have always been classified as Capped Rental (CR) machines under the assumption that they require less maintenance. Before 2006 DME (Durable Medical Equipment) under the CR classification was covered for 13 months, at which time Medicare put a lid on it [I'm guessing that's where they got the word "capped".] The user had a choice (after ten months) to take ownership or to continue to rent the machine. Medicare continued covering service and maintenance limited to that decision.

Frequent and Substantial Servicing (FSS):

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Considered more akin to full ventilators, Medicare would pay for the monthly rental fee (over \$600.00 a month) for an undetermined period of time under the assumption that maintenance was required on a continuous and ongoing basis.

Under the new regulations, not only are the ST machines now included under the CR heading, but the CR regulations have changed as well. After 13 months, ownership of CR equipment is automatically passed on to the user. Other effected equipment includes oxygen equipment (36 month cap), nebulizers, wheelchairs, and hospital beds.

Why the change? According to the Federal Register document, after years of studying the situation, they concluded that the only difference between the ST and the other machines is the “timed” function. Over a lengthy study period, no significant difference in mechanical maintenance intervals exists between machines, and therefore the FSS designation constitutes excessive payment.

DME providers countered that respiratory therapists need to be compensated for patient and machine monitoring and adjustments, as well as other services vaguely described as maintenance and respiratory care. CMS officials explained that these services are the responsibility of the patient’s doctor, not the therapist.

The bottom line for **Medicare Direct** people is this:

If you got your ST machine on or before April 1, 2006, you will become the proud owner of your machine on May 1, 2007. If you got it after April 1, 2006, you become owner after 13 months.

What do you need to do?

The change should have little effect on us once we get used to the new system. The most obvious change will be: the responsibility for our wellbeing shifts to us, and our doctors.

As the owner of your machine it will be entirely up to you to arrange for replacement mask (1 every 3 months), tube (1 per month), headgear (1 every 6 months) and disposable filter (2 per month). This is similar to getting a prescription for a medication. You get the prescription for replacement parts, present it to your local DME provider, and (just like your meds) pick them up or have them delivered as scheduled.

If the machine breaks, you will have to arrange repairs. Your machine may have a two-year manufacturers warrantee. After that, Medicare has agreed to cover reasonable costs of needed services and repairs. It will be up to you to ask your doctor to prescribe service if and when needed.

Previously, **if you needed your machine adjusted** you might go directly to your DME supplier. According to CMS, “The overall clinical care of a beneficiary who receives DME is

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the responsibility of the beneficiary's treating physician. Therefore, payment under the DME benefit does not include payment for the clinical services of a respiratory therapist or other clinicians that relate to the care of the patient.” In other words, if your machine isn't performing as well as you think it should, it will be up to you and your doctor or pulmonologist to determine if and by how much your machine needs adjusting.

Some Frequently Asked Questions:

FAQ: But my doctor doesn't know how to adjust my machine. What do I do?

Answer: I talked to Manager Janet Stephens at Breathing Disorders Services, in Hemet (951) 765-6985. She told me that her customers bring in their machine with a prescription from their pulmonologist or primary doctor and she makes the adjustment as a free service. Maybe your supplier will be as kind.

FAQ: Do I have to take my prescription to the same place I got my machine?

Answer: Debbie Richard of Montage Medical in Temecula – (888) 596-6007 – says you can take your prescription to the Medicare qualified supplier of your choice. People move, or need a close supplier.

FAQ: I heard about a more expensive ventilator that we might be able to change to. It sounds scary, is it necessary?

Answer: There has been some talk about the next step up called a Volume Ventilator (VV). While it is still listed under the FSS heading, and therefore fully covered under Medicare rules, in order to qualify for it, your current ST machine would have to be failing to meet your breathing needs. In the case of PPS related neuromuscular breathing problems, the ST machine is the perfect solution for me and for everyone I've talked to – as long as the settings are right. And, even with the VV machine, the settings have to be just right, or you won't get the best results.

[Read about how to get the settings right in the May 2007 issue of the PPS Manager newsletter.]

FAQ: What about improvements to existing NPPV ST technology?

Answer: Machine manufacturers are always trying to get a leg up on the competition. The latest trend is toward automatic machines. As you breathe into them, the little computer inside “reads” your needs and automatically adjusts itself. According to Ron Richards of ResMed (manufacturer of the VPAP III), that machine is now being used effectively for many disorders, but because a PPS patient's needs drift around through the night, the machine is unable to make a final decision as to what the settings should be. So far the FDA has not approved the new technology for our use. Mr. Richards expects an algorithm to address the problem within a year.

Medicare is unlikely to replace our existing machines until they are at least five years old, so we can look forward to some really amazing technology when our current machines need replacing.

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FAQ: It's not fair. Medicare is taking a valuable service away from us. How can we fight back?

Answer: If you don't agree with the CMS decision, and/or can't deal with the changes, write to your government representatives.

Conclusion

Things change. We change. So what else is new?

I hope this article has relieved some of the stress the Medicare change may have caused. If you have questions, please write or call me. If any group of people is expert at compensating for unexpected change, it's us. Let's make this work in our favor.

[Look for "NPPV – A New Understanding" in the May issue of the PPS Manager Newsletter]

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Donate your Body to Medical Science Now – Why Wait!

By Rick Kneeshaw

Recently, the Medical School at the University of California San Diego asked me to be a volunteer patient. The school was looking for folks with neurological conditions willing to allow second year medical students to practice examining under the supervision of an experienced neurologist. They were looking for living patients, not dead ones, and since I had polio as a child and was still breathing I was doubly qualified!

Now, I complain about doctors as much, or more, than others with PPS, so I thought this might be an opportunity to do some constructive teaching of my own. Perhaps I could even overcome my feelings of guilt for years of complaining about clueless doctors who say, "Post Polio Syndrome, I don't believe in it, it's all in your head."

I can now happily report that the experience was exciting and educational – for the medical students, and for me. During two teaching days, I was examined by ten neurologists and fifty nervous medical students, each with a fresh young face, each proudly carrying a brand new reflex hammer, looking for someone to whack!

During five 30-minute sessions a teaching doctor and five students would evaluate my muscle strength, test my reflexes using their new hammer, and otherwise conduct a brief neurological exam of my body. While the other students watched, each one took a turn touching my cold leg, measuring the atrophy and observing obvious paralysis, asking about the scars, and peppering me and the doctor with questions about polio and post polio syndrome. I was actually encouraged to answer questions (there is a God).

Surprisingly, all ten teaching doctors were very knowledgeable about polio and PPS and took time to explain it to the students. There was never hesitation about whether PPS was real. Subtle side effects like difficulty with bowels, fasciculations, tremors, and breathing difficulties were also discussed.

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In addition to the essential medical skills being taught, each student was expected to introduce themselves, explain why and what they were going to do to me before they examined me, and even wash their hands in my presence before and after they conducted their mini exam.

By the end of each day my body was sore and tired from all the hammer strikes and muscle tests, cold from sitting on an exam table half clothed for 4 hours, but my heart was warm knowing that the facts about PPS are being taught in medical school today, and that in the future there will be at least 50 new doctors out there who were taught about PPS in medical school. And I helped. I don't feel as guilty now, either.

If you'd like to put your body to good use sooner rather than later, why not help out. After all, it's not every day someone wants your body and is willing to pay \$50.00 for it.

To volunteer contact Marty Becerril, D. C.
Patient Resource Program Coordinator
UCSD School of Medicine
Office: 858.822.4464
mbecerril@ucsd.edu

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NOTES:

We need your help

We'd like to make this newsletter part of a new Non Profit Organization. If you're an attorney and would like to give us a hand, contact Rick Kneeshaw 858-566-4016 or piecon@mindspring.com

Update your e-ddress today!

Do you have an e-mail address? Have you changed it recently? Have you heard from your PPS support group lately? Well, maybe you've been lost.

Just to be sure, send an e-mail with your name and e-ddress to your local group leader. You'll find the e-ddress to send it to at the end of the Meeting Report.

The Way to Get Home Health Care

Medicaid Funds to Keep Persons Out of Institutions – Information Bulletin #187 (1/07)

Section 6086 of the Deficit Reduction Act of 2005 has not received much attention. It offers States a new opportunity to provide a full (or partial) range of community-based services for seniors and people with disabilities. Beginning now, January, 2007, States can use this new statutory provision without applying for a Medicaid waiver.

Here are some important aspects of Section 6086:

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1. It applies to seniors and people with disabilities with incomes up to 150% of the poverty level: \$14,700 for a single person and \$19,800 for a couple. These income levels are higher than many States now provide for either MA community-based waiver services or MA state plan services, and could help many seniors Social Security.
2. Because no waiver application is required, there is no excuse that the process is too complicated.
3. These services can be targeted to persons BEFORE they go into a nursing home. This is important because, nationally, 11.8% of the persons IN nursing homes went into them directly from their own homes and had NOT been receiving any home health services before entering the institution; that's nearly 155,000 people in nursing homes as of 9/30/06! Why should anyone be admitted to an institution without at least being offered and provided community-based services?
4. There is no requirement under Section 6086 that persons even meet nursing home level of care criteria.
5. There is no "cost neutrality" requirement that MA waivers have.
6. States can limit the number of persons who will receive these services, so States will be able to monitor and control the financial aspects of offering and providing the services.
7. States can concentrate the Section 6086 services in areas of the State that historically have high concentration of nursing home enrollments.
8. These services can be consumer directed.

Has your state started to offer Section 6086 community-based services? Will your state offer them? If not, how can your state continue to complain about MA expenditures, when it will not implement a program that will save MA costs by preventing many of the 11.8% of the persons entering nursing homes? [Your state's specific percentage of persons admitted to nursing homes without receiving any home health services can be found:

<http://www1.cms.hhs.gov/apps/mds/res3.asp?var=AB2&date=16>]

Source: Steve Gold, The Disability Odyssey continues. Write to stevegoldada@cs.com or call 215-627-7100
<http://www.stevegoldada.com>

Thanks to PPS of South Florida for sending this information.

MEETING REPORTS

San Diego Post-Polio Support Group

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January 14, 2007 Meeting Report

By Gladys Swensrud

Our Saturday meeting was a smorgasbord of wonderful information. To open this month's gathering, Steve Goldman led a discussion about the ways in which our lives have taken *positive* turns as a result of having had polio. Steve noted that although we each have ways in which our lives could have been different, we had no control over contracting polio, so we moved forward in positive ways, and that is what he wished to bring into focus.

The general thread, which ran through this segment of the meeting, was that the typical, type **A** personality trait, which gave us the strength to overcome our original bouts with polio, also gave our children a special understanding of how we met life's adversities with a "can do" attitude. That permeated the very being of their existences as well and translated to a similar strength in the way they approached their lives. We generally agreed that our children are strong, sensitive young people, perhaps owing, partial at least, to the way they observed us interacting with others and living determined lives in spite of any residual effects of polio.

Gladys Swensrud filled the last few minutes with a presentation on several useful kitchen gadgets designed to make life easier for the muscle challenged. She mentioned that although the kitchen was once her favorite room in the house, it is now the source of some of her greatest daily challenges. To minimize those concerns, she planned a visit to Kitchens Plus at North County Fair to see if there were some new ideas for simplifying her daily kitchen responsibilities.

The helpful staff at Kitchens Plus wandered the store with her and came up with many tremendously helpful items such as: an easy-grip ice cream shovel to replace her tiny metal scoop, several easy-to-hold handled dry-scoops of various sizes for sugar and flour canisters, and a jar opener with teeth to grip those difficult to open peanut butter jars. Gladys's experience was extremely useful to shore up some of her personal kitchen needs, and she recommended a visit to your nearby kitchen shop as an outing soon.

The next San Diego Polio Survivors meeting will be held on Saturday, March 10 at 10:00am at Kaiser Permanente's Zion Hospital location/Classroom 3. We have two scheduled guest speakers: Marty Becerril, D. C., Patient Resource Program Coordinator for U.C.S.D. School of Medicine's Professional Development Center, **and** Sue Peeters, board member of the San Francisco Bay Area Polio Survivors. This should be a resource filled, information packed meeting.

____ **The next La Jolla meeting:** ____

March 10

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

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

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

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COACHELLA VALLEY POST-POLIO SUPPORT GROUP

The February 9th meeting started with printed handouts on an important topic to all, Preparing for Disaster for People with Disabilities and other special needs, Family Disaster Planning and Disaster Supplies kits. A brief discussion of what type of natural disaster can happen to our region and if our own communities have a disaster plan.

The Braddy's shared an important story on the proper treatment of a person with "Heat Stroke". Their 37-year old daughter did not receive proper treatment and this was even from the 'professionals' that attended her. One of the results of the improper treatments is that this 37-year young lady now wears a heart pace maker!

Rita Lack was back with us after a 22-day hospital stay. Not exactly the heart operation (my miss reporting last month). Rita had a skin flap removed from her carotid artery, that was causing higher blood pressure. No surprise to PPS members the care staff needed to be educated about PPS. On a good note: one of Rita's physical therapist offered to be a meeting speaker to share and to learn about PPS!

APRIL 13, 2007 meeting speaker will be from the Community Access Center (CAC), which provides services to people with disabilities in Riverside County. There will also be printed literature and a question and answer period. We encourage everyone to attend and bring your questions. Go to www.ilaca.org for more info.

We would like our members and anyone interested in the speaker on physical therapy to RSVP to 760-329-9593 the date will be announced later. May 11, or June 08 are in the 'running'.

Barbara Hall

_____The next meetings:_____

March 9

April 13

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

For information, contact Joe Camaya stan-n-ollie@msn.com, (760) 365-3587 or Barbara Hall whall233@aol.com, (760) 329-9593

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Escondido Post Polio Group

____ The next meeting: ____

April 10

Regular meetings on the second Tuesday of even # months from 1:00 to 3:00 at Joslyn Senior Center, Dorothy Boeger building, 728 N Broadway, Escondido
For more Escondido info. call Mary Clare at 760-741-5075 or postpolio@cox.net

HEMET AREA POLIO SURVIVORS

Hi Everybody.

At our February meeting, Ron Eitzen from Miller-Jones Mortuary in Hemet filled us in on the details of making funeral arrangements before you die.

About half of the members present had been faced with the stressful situation of having to make arrangements for a loved one. Sometimes the death was sudden and unexpected giving only hours or days to make a lot of decisions. Often there were complicated issues regarding transportation of the body, additional charges, etc.

After hearing Mr. Eitzen's presentation, it makes perfect sense to me. Regardless of our age or health, we should make our own preparations. Only we know what we want, and we have plenty of time to decide on the details, and pay for it in advance. Why burden the kids.

Bunny Smith missed the meeting because her daughter, Lynn, is seriously ill. Bunny is in the process of finding a person to live in her house with her. She hopes to be able to share information on this and on her new "Life Alert" or similar home safety warning system at the March meeting.

Have fun ... Rick

____ Our next HAPS meetings are: ____

March 20

April 17

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

Riverside PPS Group

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On January 21, 2007, we lost one of our members, Kathryn Fitch. She was 82. Kathryn made it to a few of our meetings over the years, in spite of mobility issues and her age, and was always positive and wanting to be of help. Her husband, Bob, was ever faithful assisting her. Some of you may remember them in connection with demonstrating the chair lift they had on their car. Her husband, Bob, has offered to sell her 3 month-old CTM Power Chair scooter for \$900.00, and 15 month-old Go Chair scooter for \$750. E-mail Bob at robefit9@aol.com or call Judy Mahoney.

Meeting, February 17, 2007

Eight of us assembled, plus one by phone. One more tried to join us but didn't find us. If you haven't been here before, please call for directions, or check the address online at maps.yahoo.com or mapquest.com. There are two Ramona Drives, and it is easy to pick the wrong one.

There was general discussion on breathing, with mention of a recent breathing article in Rancho's newsletter.

Betty asked what topics would we like to see covered at our meetings? For topic ideas we looked at newsletters Judy has been receiving from various support groups. Pauline took a pile of these newsletters home to review, and will make some recommendations.

Our meetings will continue to have time set aside for unstructured discussion, but will focus on the topic of the month. For April our topic will be Nutrition – Diet, Vitamins, etc. We would appreciate your input on this at any time as we prepare for the meeting.

Medical Baseline Allowance

Sue brought her gas bill insert and asked if anyone knew why polio wasn't on the list of disabilities qualifying for Medical Baseline Allowance. We talked about a call-in effort to the Gas Company. One person making the request doesn't get attention, but if many people call in, perhaps that would have an impact. 1 (800) 427-2200 –web site is: www.socalgas.com

The current list reads: “Qualified medial conditions include: scleroderma, multiple sclerosis, quadriplegia, hemiplegia, a compromised immune system, or treatment for a life-threatening illness”

We received an email in January asking about meetings in San Bernardino. According to our roster, there are about 20 names that might qualify as driving distance to San Berdo. Not all of these have email. If you are interested in forming a group for the San Bernardino area, contact Rick (951- 926-5492 / PPSMan@aol.com) or Judy (951-788-9310 / PPSRiverside@aol.com).

Next meeting Saturday, April 21st at 10 am. Topic: Nutrition

___**The next Riverside PPSG meeting:**___

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April 21

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

Big Bear PPS Group

For information contact Marsha at (909) 878-3092

High Desert PPS Group

Next meetings: _____

March 6

April 10

Regular meetings: Second Tuesday of every month. Location varies.
For information contact Vi at (760) 949-6775, or e-mail BillHerold@aol.com

Polio Survivors Plus

Of South/West Orange County

The last general membership meeting of Polio Survivors Plus of Orange County featured Attorney Kim Hubbard who addressed how people with disabilities can protect themselves against fraud and abuse. A number of local, State of California and federal reference resource materials were distributed to meeting attendees.

With this March 28, 2007, PSP launches a meeting series of "Healthy Living," with Attorney Nancy Rimsha who will address the topic of:

"Managing Your Health Care & Handling Medical Appeals"

It's important to prepare for your appointments with your medical providers by:

* Making lists of items you want to cover in your brief consultations with doctors, occupational therapists, physical therapists, etc.;

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- * Keeping a daily log of your activities and new or unusual symptoms that affect your quality of life;
- * Researching (on your own) alternatives to meeting your health care needs prior to your appointment(s);
- * Practicing brevity, keeping "cool," and working with your "chosen" health care provider as a "partner" for achieving the highest quality of life that's possible; and when you need it ...
- * Bring a friend or family member with you to help you through your appointment.

When everything seems right for you, but it doesn't seem like your medical provider will give you what's needed to meet those necessities, the only option is to pursue an appeal. To effectively pursue an appeal, one must strategically prepare the facts. Many factors that affect the success of your medical appeal, so if you'd like your concerns and questions answered, submit the name of your health care plan (e.g. Kaiser, Delta Dental, etc.) and type (e.g. Medicare, Medi-Cal, Medi-Medi, PPO, HMO, etc.) as well as your question and/or a copy of your health plan's appeal process to:

Email : efminder1@cox.net AND MaLiebchens@aol.com;

Fax: (949) 830-9449; or

Bring a copy of your health plan's appeal process: to PSP's meeting on March 28.

Next meeting: _____

March 28

April 25

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

23822 Avenida Sevilla, Laguna Woods, CA

For information and to RSVP for gate entrance permit, contact: Sue Lau at (714) 639-7497 or e-mail Maliebchen@aol.com

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LETTERS

Rick,

[Regarding the January 2007 issue]

Another wonderful newsletter, and your words are so full of upwardness, of life! Thanks for writing them.

Your article on how to get pneumonia - interesting approach, and quite an effective way to get the points across! You're a good writer, Rick. When is your book coming out?

Glad you are keeping on with PPS Manager!

Judy

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Hi Judy,

Thanks for your kind words. Work on my book is slow. I'm at the point where I practically have to drop everything else to get it done. But I can't stop playing music, and you people won't let me quit doing this newsletter ☺

Have fun ... I am ... Rick

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Hey There,

I just received my Uplift Seat Assist, which is a self-powered, portable, light-weight lifting cushion and is supposed to be covered by Medicare Code E0629. It can be used in any room in the house, and lifts up to 80% of a user's weight. There are two different models available with weight ranges from 80 to 350 pounds. The seat assist features a hydro-pneumatic lifting mechanism that activates slowly as the user begins to stand. No battery or electricity is required.

I just used my seat assist for the first time last night. I found that I actually had to set it at a lower weight than my own because the first time I got up from the seat it almost catapulted me! LOL It really does work. I am hoping to take it onto an airplane with me next time I fly, as I have trouble getting up out of airplane seats.

Here is the website for Uplift: www.up-lift.com

I recommend browsing on accessible websites to find a reasonable price if you are going to purchase it out of pocket because a local dealer (Active Mobility) quoted me the price of \$239!! plus tax. Another online site price was \$139.99. I surprisingly found my seat assist in excellent condition at e-bay for \$49.99!! I received it within 7 days. For Medicare users, if you are interested in this seat assist that is the way you should go.

Later. Marion

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Hello there,

Before anything else, I would like to thank you for all your help in keeping us updated on PPS.

I contracted polio at 2 years old and have managed fairly well (albeit with the use of a left leg brace). Although my good right leg "looks" fairly normal it does not have all the strength and/or all the functionality of a normal leg. Still, it is better than my left leg that requires the use of a full leg brace for support and mobility.

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Which leads me to my question/request for assistance:

I had an accident last month resulting in my knee being swollen and apparently I damaged my meniscus. It is currently swollen and the orthopaedic doctor (supposedly very good but no experience with polio) is recommending outpatient surgery or arthroscopic surgery. I was wondering if we have any members who have had experience with a lateral & medial meniscus resulting in arthroscopic surgery. If so, could you direct me to information on any negative/positive impacts. One primary concern is a book I bought through the organization stated that one should "Preserve to Conserve". Well after this surgery - I will have to do some physical therapy which will have to exert some muscles, and I am not sure if this may negatively impact my right leg. I am pretty mobile until now and walk with a full left leg brace.

Any referral to an orthopaedic surgeon who has experience with Polio would also be helpful.

I will also be needing a new brace and I understand there is a good brace maker in San Diego. Although I live near LAX airport I am willing to go to San Diego if he is good. Please advise.

Thank you in advance for your support and any assistance you may be able to provide.
Marite Vella

[Contact PPS Manager if you can advise Marite.]

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Carol shares:

I did not notice PPS until 1981, 30 yrs after I had Polio. Oh, I did trip all of my life, but laughed it off, as I did my Type A personality, but I have been known as a "go getter," which I had to overcome with Dr. Bruno's persistent help...because in 2004, I began to lose my ability to swallow water, and painful episodes with my legs, went into temporary paralysis.

Those who had Polio are only pushing their luck if they don't slow down. It's physiological. One of my friends refuses to accept this, even though he's now on BPap 16 hrs/day. He always ran 5 mi/day, etc. Well, his skiing days were over, as well. Then, this year he said, "To heck with it; I'm going..."

Later he called me from Ruidoso, and told me that his thigh muscles were killing him but, "I made it down two hills. On the third, my knee gave out. It's so bad; I'm in the hospital here. I 'blew' my knee joint. What happened, Darlin'?"

HA! His motor neurons were screaming for protein, and rest, and the quads weren't able to get enough circulation. And they support the knee joints. So now, the orthopedic surgeons at Baylor in Dallas are loath to operate on him after doing a new sleep study, knowing the anesthesia will be a touch and go situation, unless they attempted it by local anesthesia. But the chief of anesthesia said it's still not going to be safe to try and replace the knee joint. He's done far too much, and [considering] his stubborn refusal to accept he had to "conserve to preserve"

...

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I'll be seeing him next week in Dallas, and speaking there as well. I really breaks my heart to see people who will not respect their bodies, and [protect] their health. I've seen it so many times in my healthcare career, and lost patients to this stubborn refusal to accept reality.

[Carol, you can lead a horse to water ...]

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Dear Rick,

Thank you for all your hard work on the PPS Manager.

In the last issue Fred inquired about sensitivity to anesthetics. Would you send this info to me?

Thank you for your help.

Lisa Chan

[I sent the package to Lisa right away. If you have PPS and have surgery scheduled, it's very important to give information regarding anesthetic sensitivity to your doctor, anesthesiologist, and post surgery caregivers. If you need this information, let me know. – Rick VDL]

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Rick,

This is Micki Minner in Tucson, Arizona (again!)...I LOVED your January [2007] issue of PPS Manager. I adored your "tongue-in-cheek" article about how to get Pneumonia. My husband (also a PPS'er) is also a Registered Nurse, and we laughed about your party animal bacterium line!

I think that so many people forget that it isn't just the virus or bacteria, but am glad you made the point that fatigue, and stress leave your body wide open to accept those party animals.

I am still working full-time, and my husband is retired (and put in a wheelchair), and we can tell the difference in how many virus and bacteria party in our bodies. I am now always getting everything that comes through Tucson, and even though we live together, he doesn't get the flu/virus whatever as often as I do!

Of course, I do work in a hospital, which might be why I get more of the diseases, however, before I started working in the hospital, I still got more illnesses than my husband.

Oh well, all part of managing PPS...

Thanks again Rick for all the work you do on the PPS Manager. You are definitely one really cool guy!

Micki

[Ah, shucks ... Rick]

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THANKS

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

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