Founded in 1989

The Post-Polio Support Group of Orange County Newsletter

May 2011

15231 Marne Circle
Irvine CA 92604

Website: **ppsupportoc.org**

Kaiser Permanente will commence PPS training for its physicians in early 2012

Thanks to all who completed our questionnaire last year on PPS caregivers. Your efforts provided the valuable data Kaiser needed to make the decision to do a series of Webinars (interactive training by computer) on the diagnosis and care of PPS. Their experience is that Webinars are more effective learning tools than traditional seminars and reach very many more doctors. The Kaiser physicians participating will receive Continuing Medical Education credits.

After each Webinar, Kaiser has agreed to provide us with a DVD of the Webinar. Our plan is to approach the various medical professional academies and urge them to use the DVD to develop PPS-CME training for their members. More in future issues.

Inside this Issue

Come and hear Dr. Susan Perlman present the latest on PPS research and treatment. Dr. Perlman is a renowned and respected neurologist who has been active with PPS education for patients, physicians and therapists. She directs the PPS Clinic at UCLA. **Sunday, May 15 at 2PM.** See page 8.

You can help reduce printing costs and reduce the amount of volunteer labor involved in producing this newsletter by receiving it by email. If you choose to, email editorBaldwin@ppsupportoc.org

Aging Well with Post-Polio Syndrome: Addressing Habits that Cause Sleep Problems

Researchers at the University of Washington's Aging Rehabilitation
Research and Training Center, Seattle, Washington, mcmulk@u.washington.edu

Getting a better night's sleep may not always happen, but if your sleep problems are due to medical issues, there are ways you can manage them. Many medical problems can disrupt sleep in people with post-polio syndrome, such as breathing problems, so treating them is a first step in addressing sleep concerns. Sleep apnea, or episodes

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where people stop breathing during sleep, is a very important problem to discuss with your doctor if you have this symptom. Pain, which can also disrupt sleep, is a major topic that will be addressed in a future column. Here are some physical factors that can disrupt sleep and tips on eliminating them.

Caffeine ... Caffeine often plays a role in sleep problems, because it is a stimulant that affects the central nervous system. It temporarily increases alertness and wards off drowsiness, which are also the reasons it can cause sleep problems. People who drink caffeine are less likely to sleep well than those who do not. If you have sleep difficulties, it is a good idea to avoid caffeine or limit it only to the morning. Caffeine is present not only in coffee and black tea, but also in many sodas. Check labels. Decaffeinated coffee and tea are good substitutes.

Alcohol ... Alcohol is a sedative. Although it may seem like it helps with sleep problems, it can actually cause them. For example, alcohol can help you to fall asleep, but it also disrupts the sleep cycle and the quality of sleep. The sleep you get after drinking alcohol is not restful, because it interferes with the ability to achieve and stay in the deep (so-called “Stage 3” and “Stage 4”) sleep cycles. It is a good idea to avoid alcohol altogether if you have sleep problems; at a minimum, you should limit drinking it to earlier in the evening rather than right before going to bed.

Sleeping pills ... Even though they are often prescribed to help people fall asleep, sleeping pills can actually worsen sleep problems over time. They also can depress breathing. However, like alcohol, most sleeping medications disrupt the sleeping cycle by interfering with our ability to achieve deep and restful sleep. Almost all sleeping medications, if they are sedatives, are recommended to be prescribed for a very short time (two weeks at most) to help someone sleep during a stressful time. Many sleep medications are addictive, and your body builds a tolerance to them. This is especially true of the benzodiaza-pines such as Xanax®, Librium®, Valium® and Ativan®. If you are taking a strong sedative for sleep, you should talk to your doctor about tapering off. Getting off these drugs must be done gradually and with medical supervision. Stopping abruptly can be dangerous.

Nicotine... Nicotine, whether smoked or chewed, is a stimulant like caffeine. It causes temporary alertness or jitteri-ness, and raises your metabolism. These physical changes can in turn keep you from falling asleep or disturb your sleep once you’ve fallen asleep. For these reasons and more, nicotine can contribute to sleep problems (another reason to quit smoking).

To help you sleep better, you can try:

Exercise ... Getting regular exercise and being aerobically fit can contribute to good sleep. Fitness helps the body naturally create healthy sleep cycles. However, people with sleep problems may want to limit exercise to the morning, since vigorous exercise late in the day may make it difficult for your body to start winding down for sleep. If you have sleeping problems and you aren’t already exercising, explore an exercise program.

Other medications ... Unlike sedatives (discussed above), medications for depression can improve sleep and help you get back into a more normal sleep cycle. Talk to your doctor about this to see if a prescription would be right for you. Some anti-depressants that can help with sleep are trazodone, amitriptyline, Paxil® and Zoloft®. —

The contents of this column were developed under a grant from the Department of Education, NIDRR grant number H133B080024. However, those contents do not necessarily represent the policy of the Department of Education, and you should not assume endorsement by the Federal Government.
www.post-polio.org
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Successful Bracing Requires Experience, Sensitivity

Carol Elliott Downers Grove, Illinois, carolkelliott@aol.com

Joe Ramicone is the past president of the Midwest Chapter of Prosthetists and Orthotists, a member of the American Academy of Orthotists and Prosthetists and a member of the Illinois Society of Orthotists, Prosthetists and Pedorthists. He has served as a volunteer practitioner at the 2002 Paralympic Men's and Women's Slalom and Giant Slalom downhill skiing events in Salt Lake City, Utah, and was the key organizer for the First Swing Golf Clinic for physically challenged individuals in Chicago in 2003. In 2010, he was involved with The Great Lakes Adaptive Sports organization, a track and field competition for youths with various physical disabilities that held local and national championships.

Carol Elliott is a freelance writer/editor and contributor to Post-Polio Health. She deeply respects and appreciates the good work of orthotists everywhere.

I experienced polio in 1953 at age 2 that resulted in right lower limb paralysis. I have worn a KAFO (knee ankle foot orthosis) my entire life. An "orthotic" device is a brace or splint for support, immobilizing or treating muscles, joints or skeletal parts that are weak, ineffective, deformed or injured. A Certified Orthotist is a healthcare professional skilled in evaluation, design, fabrication and fitting of orthoses (braces) and other devices to straighten or support the body and/or the limbs.Like most polio survivors who use assistive devices due to lower limb paralysis, I am well-acquainted with the need to find quality practitioners or orthotists. This presents a unique challenge to both groups. The effects of aging, muscle overuse, joint pain and soft tissue damage, weight loss or gain for polio survivors require constant adjustments to their braces. Sometimes this results in a doctor's prescription for a new leg brace. Often, the polio survivor is faced with the challenge of trying newer materials and technologies to "correct" weight-bearing realignment issues. Some people want what they have always been comfortable with, even if it means rejecting an upgraded leg brace because it might require a painful "breaking-in" period and getting used to a "new normal." Some people might prefer the orthotist to "accommodate" their preferences with an exact duplicate of the braces they have grown up with over the years.

Having worked with many, I think a good orthotist should be experienced and sensitive. Over the years my orthotists have been a diversified group. The one quality that I consistently admire is their genuine desire to fabricate what would be the best orthosis for the patient's unique situation - a real challenge in the older polio survivor. Most importantly, I look for orthotists whose goals and mine are the same: a brace that makes me feel secure and comfortable.

Joe Ramicone, the orthotist I have seen for the last four years, fits that criteria, and I asked him some questions that may be

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The American Board for Certification in Orthotics, Prosthetics and Pedorthics is the accrediting agency for Certified Orthotists and Certified Prosthetists. Those certified have a strong science background and formal instruction in biomechanics, kinesiology, pathomechanics, material science and gait analysis. Practitioners must have a minimum of a bachelor's degree in orthotics and prosthetics or a bachelor's degree in another field and have completed a 12-month accredited residency program. To check out the credentials of an orthotist, go to www.abcop.org.

useful to other polio survivors who find themselves in need of orthoses.

PHI (Post-Polio Health International**): Do you find that most polio survivors have fairly definite preferences about trying upgrades? Are they willing to leave the old behind? How do you best approach polio individuals who have worn KAFOs all their lives?**

JR: Most polio survivors have a good idea of what they want in a new orthosis. The most common request is to see what is new and then to be fit with a device similar to what they've had. At this point in my career, when it comes to the polio survivor, I change very little in a new orthotic design. Most of my trials with new technology have not ended up with a better outcome. I believe that polio individuals want a newer technology, but also like the familiar feeling of their existing KAFO.

One example is the use of a polymer KAFO to replace a conventional, or metal and leather, KAFO. The polymer system is a more modern approach to fabricating an orthosis. It is has the advantages of being lighter and easier to adjust or change over time. Most of the polio survivors that I have tried to convert feel that the polymer system is too hot and not as rigid as their metal and leather design. I am always willing to try new technology, but in the case of a long-time user, I will express what I have learned from previous experience and need to hear from them that they are willing to make a change.

PHI: What do you teach new orthotists treating polio survivors for the first time? How do you help them therapeutically differentiate between fabricating a "textbook" KAFO, versus a uniquely customized bracing system that fits the patient's needs for familiar comfort?

JR: I instruct the resident orthotist to observe the patient walking with and without their orthosis. We perform a muscle and range of motion test and then observe their bodies looking for redness, callusing or other signs of excessive pressure that may be caused by their existing orthosis. We want to insure that the new orthosis fits comfortably. We will also evaluate the person's upper extremity dexterity and cognitive ability to insure that the patient can independently don and doff the orthosis.I then ask the resident to listen to what the individual expects from the new orthosis. We discuss the functional deficits that we see and the orthotic modalities to treat those deficits. For example a polio individual may need to have a KAFO with a locked knee for stability when walking. There are many different joints that will accomplish this goal. Some require two hands to use, and others will employ a trigger release that can be activated with one hand. We then solicit the person's input regarding vocational and recreational goals and urge him or her to

play a role in the design of the new orthosis.

PHI: Have you fabricated braces for a polio survivor who has never worn a brace before - someone who has been ambulating independently for years, but is now experiencing new muscle weaknesses and fatigue due to post-polio syndrome? What type of bracing do you recommend for the first-time brace wearers, and how has this experience played out for them?

JR: Yes, I have fit "first braces" on polio survivors. The design is based on their pathomechanics and muscle weakness. We want to control the joints and motions that lead to instability and at the same time allow motion that is beneficial. The usual design is a polymer design. Most first-timers do well with this polymer, also known as a plastic system.

PHI: How has your volunteer experience with disabled athletes strengthened your ability to assess orthotic needs as people are faced with the challenge of improving mobility in their lives?

JR: The key to a successful outcome is to design an orthosis with the least amount of control and restriction that still accomplishes the goal. I tell resident orthotists to manage only what needs to be managed, and leave the rest alone, which is easier said than done. Each individual has a different vocational and recreational activity level. For example, an individual who does not do sports, but just wants to be able to move about at home or office may do well with an all-aluminum KAFO. It is lighter than a steel design but not as durable. A very active individual may require a carbon fiber orthosis. This material is light and strong but not easily adjustable.

Some people may also be able to adapt to part of their deficit or not require orthotic management during specific activities. It is important to review the rationale for the orthotic design with each person and allow them to tell you what they need the orthosis to do. —

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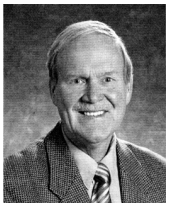
Ask Dr. Maynard



Question: **Has there ever been a study of whether antidepressants help relieve muscular pain and fatigue?** Is it a plausible treatment for people who have had polio?

A: There have been studies showing reduction of fatigue and pain (not specifically muscular pain) among depressed patients treated with antidepressant medications, but none considered pain as a "primary treatment outcome." Depressed mood was always the primary goal of treatment. Fatigue, pain, poor sleep, headache and other bodily symptoms are usually considered to be manifestations of the primary abnormal condition -depression.

I am not aware of any studies which specifically treated post-polio patients with antidepressant medication. I do know many physicians (including me) who have treated post-polio patients with antidepressant medications primarily for the purpose of helping them better cope with disabling pain and/or fatigue. Particularly when poor sleep and a general sense of hopelessness/despair about their condition are present, even if they don't "feel depressed" themselves, a careful trial of treatment with an antidepressant medication can be worthwhile.

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It is always best that these patients be evaluated and possibly treated by a clinical psychologist or other mental health professional, either in combination with medication or as an alternative. Cost and access to counseling are common barriers to this approach, as is the attitude of the patient toward mental health treatment. Support from family, friends, post-polio peer groups and spiritual counselors can be helpful. Several of my patients experienced resolution of their PPS symptoms with this holistic approach, which usually also involves lifestyle changes.

Question: **I am a polio survivor with PPS. Recently I began to suffer severe knee instability, but a sports medicine specialist recommended against braces, saying they would inhibit the muscles from regenerating. It seems to me that polio-atrophied muscles will not regenerate anyway and that braces would at least help to prevent collapse. Your thoughts?**

A: If your knee instability is a result of polio-involved muscles around the knee weakening - especially the quadriceps muscle that extends the knee and must be sufficiently strong to prevent its buckling - then I totally disagree with the specialist who recommended against a brace.

You will need a brace to stabilize the knee joint and prevent its collapse during walking. There are several different brace designs that can be considered, in addition to a traditional "locked-knee" brace, and the optimal brace will depend on your overall strength, alignment issues in adjacent joints and your functional needs.

You are right that doing nothing and waiting for muscle strength to improve by regeneration does not make sense for a polio survivor. If your knee instability is a result of ligament looseness, bracing may still be needed if the quadriceps muscle was significantly affected by polio and is very weak and/or unable to be strengthened by exercise. Please see a physical medicine and rehabilitation specialist familiar with post-polio syndrome for a second opinion. —

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Kaiser responds to our complaint on Medicine Container Caps

Our goal is to provide safe, accurate and convenient pharmacy services to our members. I learned that in the local (non mail order) pharmacy setting, some exception requests for non-safety caps can be manually fulfilled but many cannot. This is primarily due to the high volume of prescription medications that are filled by auto packers and supporting system limitations. That is why though a member's request may be flagged, it may not be fulfilled as requested at this time. This concern will be brought to the attention of the team that oversees this process to determine if potential enhancements could be made in the future. For mail order prescriptions, I learned that convertible caps are placed on the bottles as a child resistant cap and can be changed to a non-safety cap after being removed the first time. The center of the cap needs to be clicked down so that it will be non-safety. This requires the package to be opened once as a child resistant cap. Automated equipment is used to pack some prescriptions and the system is not capable of installing a non-safety cap. The convertible cap was determined to be the best compromise to providing a non-safety cap when it is required. See the following information sheet about the convertible caps. Members can also request that the cap be changed at the local pharmacy and/or ask for extra regular non-safety caps from the pharmacy to have available at home to put on their mail orders.

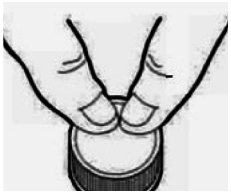
Members may also contact Member Services at 1(800)464-4000 or on line at kp.org for assistance.

****NEW** Convertible Cap on Amber Bottle Prescriptions**

In our efforts to provide you with the safest, most convenient and user-friendly packaging, we are pleased to introduce our new prescription bottle closures. During the transition to the new bottles and caps, you may find one or both styles included in your order. For those of you who desire a regular, easy-open mechanism, our new cap can be quickly and easily changed from a child-resistant closure to a standard opening cap by following these simple steps:

STEP 1: Remove the cap from the container and place it flat on a table.

STEP 2: Gently push down with steady pressure using your thumbs on the printed center of the cap as shown. The center will snap down into a lower alignment. You will feel and hear the cap move when it snaps down.



STEP 3: Replace the cap back onto the container. The cap will now simply screw on and off without requiring you to push down when turning.

You can change the cap back to child-resistant operation by pushing down on the raised rim on the cap until it snaps back down level with the center.

Kurt Drumheller, Director, Member Relations
California Member Services, Kaiser Permanente

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

How to contact OC Support Group

Call us for information:
Marte Fuller **562-697-0507**
Marilyn Andrews **714-839-3121**
Newsletter co-editors:
Baldwin Keenan 949-857-8828
keenanwhelan@cox.net
Janet Renison 949-951-8613
renison@cox.net

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

Website: **ppsupportoc.org**

Special thanks to Kay Lee Carey, Stella Olivas, Gertrude Mikus, Barbara Smith, Anita Contreras Cano, Jack Delman. 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

JOINT MEETING with Post-Polio Support Group of Orange County
(see map bottom right)

SUNDAY May 15

Dr. Susan Perlman

2pm - 4pm

Orange County Meeting

SUNDAY May 15

Dr. Susan Perlman

Listen to her review of the latest PPS research and treatment.
Ask her questions.

2pm - 4pm
See map below

Future Rancho SG Meetings

Saturday June 25th

Annual Picnic

2pm - 4 pm

Saturday July 23rd

TOPIC TO BE DETERMINED

Future PPSG of OC Meetings

Saturday June 11

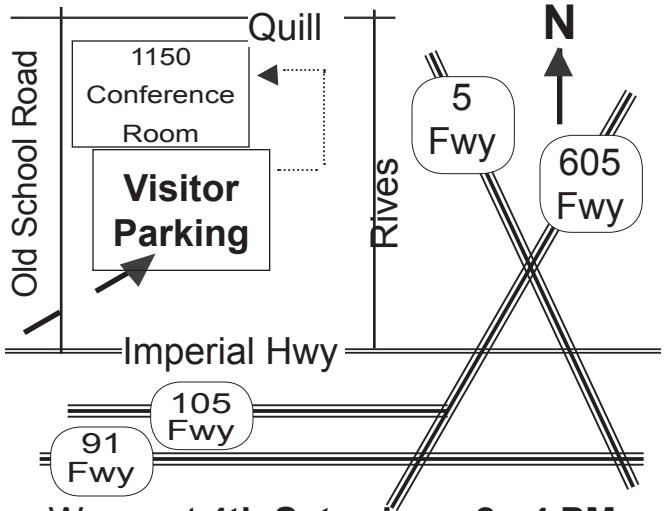
Van Conversions

Saturday July 9

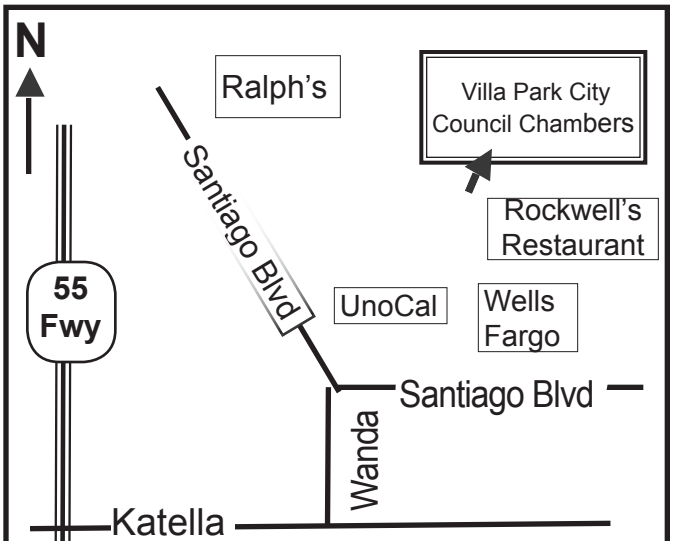
Sharing of what has helped us live with PPS

Saturday August 13

Indoor Picnic and continuation of sharing



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



We meet **2nd Saturdays** 2 - 4 PM
Villa Park Council Chambers
17855 Santiago Blvd. Villa Park

May meeting usually 3rd SUNDAY
December at Rancho in Downey