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The Post-Polio Support Group of Orange County Newsletter

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Anesthesia Use in Polio Survivors:
What's New?

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Do we know anything new about anesthesia for polio survivors? By reviewing reports in medical journals we find that in the last two years, 2008-2010, there were five case reports (each about a single post-polio patient having anesthesia) in the medical literature and one study of a group. We will look at useful aspects of these cases and also comment on two other aspects of anesthesia care that are important.

Three of the five case reports were about regional anesthesia (RA). Regional anesthesia means that a local anesthesia drug, such as lidocaine, is injected to numb nerves in the back (spinal or epidural) or other body locations such as arms or legs (various nerve blocks). It is very safe and is preferred to general anesthesia, because it blocks the pain signals coming from the surgery site to the brain. This is very favorable for patients' well-being. However, some operations can't be done with regional anesthesia. It is often technically hard to do RA in post-polio patients with scoliosis, especially if Harrington rods are present.

There is a new tool to help place RA: portable ultrasound (US) devices that help anesthesiologists find exactly where to administer the anesthesia drug. This technique is now commonly used in the United States, especially in teaching hospitals. One of the five cases was the first to report using US to place a spinal anesthetic in a post-polio patient with Harrington rods. Another case of regional anesthesia involved severe scoliosis and reported using a computed tomography (CT) scan to look at a post-polio patient's back anatomy before trying spinal anesthesia. Both techniques helped the anesthesiologists know where to place the needle for local anesthesia successfully and easily. The third case report on regional anesthesia was about a nerve block of the leg for postoperative pain relief after surgery on that leg.

The group study was from Brazil and reported on 123 patients having 162 operations, mostly orthopedic surgery. Mean patient age was young – 35 years, and only three patients had serious medical diseases in addition to having had polio. Regional anesthesia was used for 64 percent of patients. No significant anesthesia complications occurred. These patients were followed for 22 months

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postoperatively, and there was no change in neurologic status.

This study documents that young post-polio patients do well during anesthesia, especially with RA. However, American patients are much older, in their 70s and 80s, and so also have diseases of aging, such as heart disease, diabetes and hypertension, all significant for anesthesia risk. Often, these diseases of aging are much more important than any post-polio issues. So, we still need a large group study of the U.S. polio population during anesthesia.

What do we learn from these reports? First, this is increasing evidence that RA can be safely used in post-polio patients. And, so far, there is no evidence that PPS gets worse after RA. (This had been a concern after inflammatory proteins were found in the spinal fluid of some post-polio patients.) Technical difficulties can be overcome by using US or CT imaging. Also, regional anesthesia can safely be used for post-op pain relief. So polio patients can experience the many benefits of modern anesthesia care!

The importance of two other aspects of anesthesia care for post-polio patients is becoming clearer: the need for preoperative pulmonary function tests and sleep apnea issues. Respiratory muscle function gets worse as we age, especially for those who had polio. It is important to know what a particular patient's pulmonary status is before most operations, especially upper abdominal or chest operations. This is measured with pulmonary function tests (PFTs) by a pulmonary physician. Those who used iron lungs should definitely have pre-op PFTs, because they seem to be at higher risk for post-op respiratory failure. Lung function should be optimized by treating any infection, controlling bronchospasm and assisting coughing before high-risk patients have major surgery, and a pulmonologist needs to be involved in the post-op care.

Sleep apnea is common in post-polio patients, and many need CPAP/BiPAP devices. Sleep apnea is well-documented to be a risk factor for anesthesia incidents, both at the beginning of anesthesia and, especially, at the end of the case as patients begin to breathe on their own. Useful guidelines are in place to improve safety during anesthesia. Patients with sleep apnea, especially those on CPAP/BiPAP, should let the surgeons know this early in the surgery scheduling process, so they can alert everyone on the surgical team. Patients should bring their CPAP devices to the hospital and, after the breathing tube is removed, CPAP should begin. This requires someone to set up the machine, usually a respiratory therapist. If regional anesthesia is used, the CPAP device can even be used during the procedure, although not all anesthesiologists are comfortable with this.

Should we make any changes in the present recommendations for anesthesia for polio survivors? Regional anesthesia appears to be safe for post-polio patients, and the benefits – in terms of pain relief and anesthesia safety – are worth a possible small risk. So, the recommendations stand as is. It is essential to realize that the recommendations are not based on actual data; there is no significant data yet about how polio patients actually do during anesthesia. See the sidebar for other resources about anesthesia.

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Promoting Positive Solutions

Question: People in my support group are always trying to get me to talk about the past. I was in an iron lung and remember little, but, frankly, I don't WANT to remember it all. I would rather live in the present. Is this OK?

Response from Rhoda Olkin, PhD:

When is it important to talk about the past? The bottom line is that this question can only be answered by you. What works for someone else is irrelevant. I cannot help noticing how many people feel qualified to tell other people how they should do things (e.g., how to properly mourn or how to be less anxious or how to load the dishwasher!). Giving advice can be helpful to the receiver, but only if the advice is based on a thorough knowledge of you and what makes you tick, rather than on what has worked for them.

So, since you have to decide, ask yourself some hard questions:

(a) Are you having symptoms of depression or anxiety? Are these symptoms new, or recurring, or long standing?

(b) Are there areas in which you feel you are functioning below par, such as socially or with family?

(c) How would you rate your overall life satisfaction? Are you reasonably content? Do you constantly feel like something is missing?

(d) When you tally up the things that are important in life – family, intimacy, work, accomplishment, community, home, meaning – do you generally feel a sense of satisfaction, or a sense of disappointment?

(e) Are there people from your past that you still feel angry at or estranged from? Are there lingering feelings of animosity that you are having trouble letting go of that seep out occasionally?

(f) Do you have trouble with emotion? Do you veer away from any emotional topics? Can you cry, or do you feel like crying and cannot cry, or never cry? Can you tell people who are important in your life "I love you?"

Do you blow up suddenly and feel like there is a well of rage inside you? Do you find yourself in many battles, large and small?

These are questions that can help you figure how your past might be affecting you now. If your answers to these six areas seem to indicate that you are a well-functioning, predominantly content person with good relationships, then it would imply that the past is past and can keep its distance. But if your answers show areas of difficulty, and these are areas in which you would like to see change, it might be worth dredging up past memories so that they can be laid to rest.

The purpose of talking about the past is to get through it. Think of it like a big muddy puddle too big to skirt around. If the puddle is behind you, move on. If it's in front of you, then sometimes there is no way to move forward without slogging through the giant puddle; pack snacks.

Response from Stephanie T. Machell, PsyD:

Like everything, it depends.

You have a choice about whether or not to remember what happened to you, as well as whether or not to talk about it. You have a right not to talk about or remember what happened to you and to decide to live in the present. No one has the right to force you to do otherwise. And especially if your memories aren't causing you problems, not talking

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about them may be the wisest course of action.

If you don't want to talk about your polio experience, doing so because others pressure you won't be helpful. They may be pressuring you because they know that talking about their experiences has been helpful to them, and certainly research and clinical experience both show that talking about difficult experiences in a support group setting can be helpful. When others can relate and identify with what you have been through, you feel less alone – and feeling alone and unable to communicate was a key part of the polio experience for many people.

But doing this doesn't help everyone and can even be harmful, especially when something is shared that the person regrets, or new and more painful memories are evoked but not ad-dressed, or the response of the support group is less than empathic. Repeatedly telling and hearing stories of traumatic experiences can itself be re-traumatizing. And because a support group isn't meant to be therapy, there is usually no one present who can help if a negative experience occurs.

Paradoxically, sometimes you have to remember what happened to you in order to live fully in the present. People with post-traumatic stress disorder are stuck in time and unable to move forward until they have processed what happened to them. If you find that your memories of being in an iron lung intrude when you would rather they didn't, or if you find that you are fearful of remembering rather than preferring not to do so, you may need to talk with a mental health professional to determine whether not remembering what happened is the best course of action for you.

In my practice, I see many polio survivors who were traumatized by what happened to them. It has been helpful for them to work on remembering what happened and on making meaning out of it in order to move on. I have been told that doing this work has improved their PPS symptoms, especially fatigue. I believe that this is so because holding memories out of awareness takes energy, and people with PPS can ill afford to waste energy.

People who experienced polio often lost privacy and the right to determine their own needs. Deciding whether and where to talk about your polio experience is part of regaining those.

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RESEARCH:

Aging Well with Post-Polio Syndrome:

Don't Let Fall Prevention Fall through the Cracks

Researchers at the University of Washington's Aging Rehabilitation Research and Training Center, agerrtc@uw.edu

Falling in older adults is a big public health problem. Injuries that result from falling in older adults are serious, life-changing, costly, potentially fatal. In the United States, deaths from falls is the leading cause of injury-related deaths in adults over the age of 65.1 In 2000, the incidence of falling injuries was estimated to be 10,300 for fatal and 2.6 million for non-fatal injuries in adults over the age of 65.2 Both fatal and non-fatal injuries from falling increase with age among older adults.3 The direct medical care costs of treating injuries from falling in the elderly is estimated to be $0.2 billion for fatal injuries and $19 billion for

non-fatal injuries.2 The economic cost for rehabilitation after falling is even greater when stays in a nursing home, assistive devices (canes, walkers, etc.) and physical therapy are considered. Once an initial fall occurs, it can lead to a fear-of-falling, which is associated with avoiding daily activities as well as physical activity.4 This, in turn, becomes a troubled cycle as lack of physical activity increases the risk of falling.5

Polio survivors have a variety of symptoms that are known risk factors for falls in older adults and people with neuromuscular diseases such as muscle weakness, joint pain and fatigue. One study showed that the rate of polio survivors who fell at least once in the past year was four times that of other adults over 55.6 This study also found polio survivors report falling more often in the afternoon and inside the home.6 Three important predictors of falling were identified for polio survivors – a) Problems maintaining balance, b) Weakness in knee extension in the weakest leg, “knee buckling” and c) Fear of falling.6

Polio Survivor Data from our Survey

Many Post-Polio Health International readers participated in our survey that asked some questions about falling. Here are the responses of people with post polio syndrome:
--242 (54%) reported a fall within the last 6 months.
--385 (86%) are concerned about falling.
--366 (82%) reported not doing things because of fear of falling.

What can you do to prevent falls? Knowledge is half the battle. Falls inside the home have been linked to stairs with four or more steps, slippery floors, sliding rugs, low lighting levels, missing handrails, uneven flooring and obstructive walkways. Falls outdoors are often linked to walking on uneven or cracked sidewalks, curbs or streets. Other fall prevention tips include:
--Have your vision and hearing checked regularly.
--Talk to your doctor about side effects of medication that could affect coordination and balance or increase weakness.
--Wear rubber-soled and low-heeled shoes that fit well and fully support your feet, and replace worn cane and crutch tips.
--Avoid wearing socks when walking inside on hardwood or linoleum flooring. Socks with the grippers on the bottom or wearing Crocs while inside help prevent indoor falls.
--Be careful when walking outdoors on wet or icy sidewalks. Carry your cell phone on walks. Try to anticipate fatigue and bring what you might need for more support (cane, walker, etc.) or even a friend or family member.
--Ask your doctor what exercises you can do regularly to maintain strong bones, strength and flexibility. Exercise that improves balance and coordination (Tai Chi or Yoga) are most helpful.
--Keep your home safe – remove things you can trip over (shoes, papers, books, clothes) from stairs and high traffic areas. Keep clutter down!
--Install handrails or grab bars in your bathroom or other frequently used areas where you may need extra support (stairs and hallways).
--Improve the lighting in your home. As you age, you need brighter lights to see well

The U.S. Centers for Disease Control and Prevention has produced brochures titled “What YOU can do to prevent falls” and “Check for Safety: A Home Falls Prevention Checklist for Older Adults” available in Eng-

lish, Spanish and Chinese. **www.cdc.gov/ncipc/duip/spotlite/falls.htm**

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Rules for Last Resort Heath Plans

Noam Levey - (reporting from Washington DC) Los Angeles Times

The Obama administration, expanding a program created by the new healthcare law, moved Tuesday to make health insurance more affordable and accessible for Americans who have been denied coverage because they are sick.

Across the country, the federal government is reducing premiums on special coverage available to uninsured people with preexisting conditions such as cancer or diabetes.

And the administration is loosening restrictions on who can sign up for so-called preexisting condition insurance plans. These plans were created by the health overhaul that President Obama signed last year. They are meant to provide temporary aid to sick Americans until 2014, when insurance companies will no longer be allowed to deny coverage to people who are sick.

But the number of people signing up for these plans has lagged, in part because of high premiums and stringent eligibility guidelines.

Now, federal officials estimate, premiums in some states could come down as much as 40%, thanks to a more refined analysis of what plans should charge. Applicants will still have to show they have been without coverage for at least six months. Moves to step up efforts to get people into these plans drew praise from several patient groups, including the American Cancer Society's Cancer Action Network and the American Heart Assn.

The administration is directly slashing premiums in the Dist. of Columbia and most of the 23 states that have elected to have the Fed-

eral Government run their health plans. The remaining 27 states, which each run their own plans, will be able to reduce premiums as well.

Additionally, the administration will no longer require applicants to furnish a letter from an insurance company showing they have been denied coverage. Instead only a letter from medical personnel stating that applicants have a medical condition. Applicants will still have to shown that they have been without medical coverage for six months.

The moves to step up efforts to get people into these plans drew praise from several patient groups, including the American Cancer Society and the American Heart Assn.

The expansion of pre-existing condition insurance is made possible by $5 Billion that was set aside in the new law. Additional info about signing up for a preexisting condition insurance plan is available at **www.pcip.gov** or by calling (866) 717-5826.

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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:
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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 the following donors: Barbara Wood, Carol Purington and Betty Thompson. 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

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Rancho Los Amigos Meeting

Saturday, July 23, 3011

Polio Documentary: The Last Word

Orange County Meeting

SATURDAY,

July 9, 3011

Sharing what has Helped us Live with PPS

Future Rancho SG Meetings

Contact Rancho Group for future Meeting Info.

Would you prefer to receive newsletter online? Please email: editorbaldwin@ppsupportoc.org

Save a tree
Save $$$

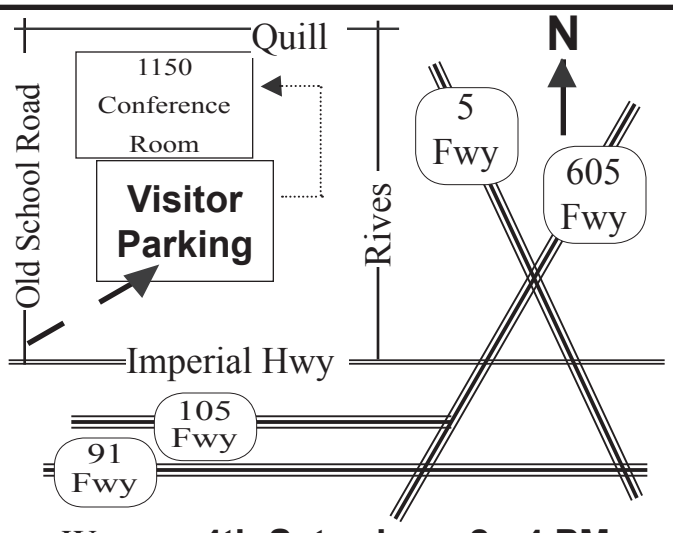
Future PPSG of OC Meetings

Saturday

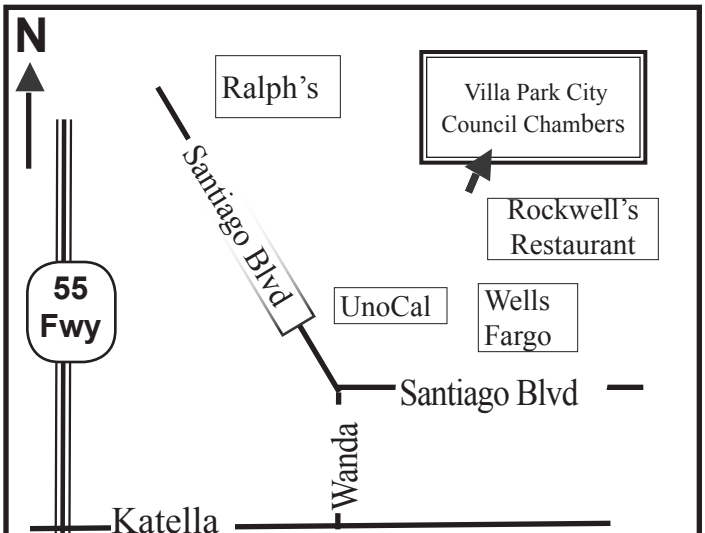
August 13, 2011 - Indoor Picnic and Continuation of Sharing.

September 10, 2011 - Nutrition

October 8, 2011- HICAP - Changes in Medicare



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 on a SUNDAY
December at Rancho in Downey