



Rancho Los Amigos

Post-Polio

Support Group

Newsletter - February 2011

Treating Polio – Now and in the Future

Including research from around the world

With Susan L. Perlman, M.D.

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University of California, Los Angeles

Presented at the Orange County, CA. PPSG meeting, May 23, 2010

Reported by Mary Clarke Atwood

Editorial assistance by R. Daggett and S. L. Perlman, MD

Dr. Perlman has learned about PPS from her patients – more than 500 of them in the last two decades. We always look forward to this annual presentation when Dr. Perlman generously shares her time and energy with local polio survivors.

This year's review begins with patient care guidelines and includes the exciting work being done with stem cells. Although there is not yet a group working with stem cells in patients with post-polio in the United States, there has been a great deal of stem cell work in patients with other neurological disorders. What is learned from them may also apply to post-polio. Other research topics include mental and physical fatigue, pain, and predicting which polio survivors will develop polio problems and who will be spared.

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Standard Patient Guidelines

Everyone needs a good primary care doctor, a knowledgeable physical therapist, and attention to good general health practices (weight management, exercise, appropriate assistive devices, relaxation training, sleep hygiene, emotional health). If a survivor has symptoms that impinge on these areas, they can be directly attacked to improve quality of life.

These standard polio survivor guidelines of the last ten years are still valid:

- Make sure your symptoms are polio related. They may be due to another medical or neurological illness or to orthopedic problems, which must be identified and treated. New symptoms in a polio survivor are only related to polio about 1/3 of the time.
- Treatment of other illnesses in a polio survivor must be monitored relative to the sensitivities of PPS (e.g. surgery, chemotherapy, use of cholesterol lowering medication).
- Polio survivors with symptoms of PPS must take care to modify lifestyle and use rehabilitation medicine or services to develop a program of appropriate non-fatiguing exercise and reconditioning, assistive devices, pacing of activities, and finding their own limit. They need to work with somebody who is knowledgeable about rehabilitation to address these issues.

Caution: Do not push yourself past the limiting point of pain and fatigue.

No one is talking about “Conserve to Preserve” anymore. If you are a polio survivor and are beginning to experience fatigability and weakness, nobody should recommend that you stop doing everything, to never exercise again and get a wheelchair.

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Why Increase the Awareness of Post-Polio?

Doctors treating polio survivors need to be aware that these patients are going to be different from patients who never had polio. Polio survivors report poorer functional status and poorer health-related quality of life than non-polios.

The life-altering effects of post-polio have not been adequately addressed by health care providers. They are not aware that they actually have tools they can use right now to help polio survivors with some of these unique problems.

Many publications indicate that polio survivors are best served in multidisciplinary clinics staffed by knowledgeable professionals. We need to make this known to others.

Will Healthcare Reform Make these Guidelines Achievable?

A personal experience:

Dr. Perlman recently saw a typical polio survivor with PPS. This patient had been seen in clinic during 2007-2008 and returned two years later.

Those earlier visits included recommendations for:

- physical therapy to develop a non-fatiguing home exercise program
- a sleep study for symptoms of obstructive sleep apnea possibly contributing to daytime fatigue.

However, a perfect storm of potential rationing and misinformation followed:

- The patient's HMO approved physical therapy but only for treatment of what appeared to be carpal tunnel syndrome. There were only the minimum number of treatments and that was it.
- No home exercise program was developed.
- No counseling about activity modification and pacing was achieved.

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- A sleep study was done confirming obstructive sleep apnea. But the physician in charge counseled that the mask to assist breathing would be very uncomfortable and it could take the patient a year to become satisfied. With a build up like that, the patient chose not to try it.

The patient returned to Dr. Perlman two years later with the same complaints: symptoms of sleep apnea, daytime fatigue, plus weakness and fatigability in muscle areas - all because of potential rationing and misinformation.

There is no excuse for this, but it happens all the time. Polio survivors need to be aware and proactive with health care providers. Bring them information, but don't overwhelm them while being firm. Show them what has been published defining the standard of care for a person with post-polio syndrome.

Will Dr. Perlman's recommendations be provided this time? The patient has a new HMO, so time will tell.

Limited treatment and misinformation are very frustrating because this patient could have had two years of improvement instead of continuing and probably worsening personal health status.

Polio Vaccine

Dr. Perlman believes that polio vaccinations need to be continued because the virus is out there. Just recently in Los Angeles there has been an outbreak of mumps because some people get lazy, or are afraid, and don't get the vaccines for their children. So mumps comes back; polio will come back.

Globally, the number of new polio cases registered in the first four months of 2010 is down to 56, which is a 75% drop from the same period last year.

- In Nigeria only two children have been paralyzed by wild polio virus compared with 123 during the same period in 2009.
- For the first time in India, there has not been a single case caused by the most virulent polio viral type for four months straight.

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Editor's Note: Centers for Disease Control (CDC) - Outbreak Notice

Polio Outbreak in Tajikistan, Cases in Russia
Risk of Spread to other Central Asian Countries

This outbreak represents the first importation of polio in the World Health Organization (WHO) European Region since it was certified polio-free in 2002. As of October 14, 2010, the Tajikistan Ministry of Health has reported 706 cases of acute flaccid paralysis. Of these cases, 458 have been laboratory-confirmed as polio. Russia has reported 14 polio cases to date, five of which are linked to travelers. <http://wwwnc.cdc.gov/travel/>

Research around the World

United States, Canada, Spain, Sweden, Israel, France, and The Netherlands

Stem Cell Therapy

Lou Gehrig's disease (ALS) research is looking at problems of upper motor neurons, typically spared in post-polio and lower motor neurons, which are typically affected in post-polio. These neurons are both being targeted with stem cell therapies in ALS patients. The nine ongoing therapeutic stem cell trials look very promising, both in Europe and one study in the United States.

The U.S. group is spearheading an ALS trial with stem cells derived from bone marrow. These results should open the doors to similar treatment trials in post-polio because the cells are the same, the target is the same, and ideally the outcome would be the same.

Researchers in the U.S. and some scientific colleagues in Europe are working on ways to make stem cells behave like nerve cells, and to make them go to the part of the nervous system in which they are interested (spinal cord, basal ganglia, memory centers) and do what they are supposed to do.

It is important to point out that some of the fringe groups in China and Costa Rica may not have done as much advance preparation of the bone marrow or umbilical

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cord stem cells. Perhaps the preparation may not have been the right kind, they may not have been modified in the right way, or they may not have been stimulated with the right growth factors. In fact, China has abandoned treating ALS patients with stem cells because that didn't work.

Although our U.S. stem cell studies for Parkinson's disease and ALS began three or four years after the Chinese, we are now working with stem cells whose behavior can be predicted and are assured they will not cause cancer.

Dr. Perlman expects to have much more information on stem cells when she speaks to this group again on Sunday, May 22, 2011.

Quality of Life

A study from two post-polio clinics in Israel found that approximately 70% of the participants expressed the belief that exposure to up-to-date information about post-polio, as well as participation in social activities, might improve their quality of life. Dr. Perlman pointed out that a support group provides those things.

Reviews and reports from other large polio clinics have also shown that education and getting people to take control of their symptoms and condition definitely improves their quality of life.

This study from Israel concluded that information about the physical and mental components of polio survivors, as well as the desire to partake in specific activities for polio survivors, may serve as a basis for the operations and prioritization of service providers. Dr. Perlman recommends including the importance of this information on grant applications.

Fatigue

Eighty-percent of polio survivors with new symptoms have fatigue, or pain, or both. Dr. Trojan's group in Canada studied General, Physical, and Mental Fatigue to determine what modifying factors could be changed and which could not.

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These non-modifiable factors, which seemed to have an effect on general fatigue, could not be changed:

- respiratory function
- fibromyalgia
- muscle strength
- age
- time since acute polio

In this Canadian study there weren't any non-modifiable factors which seemed to correlate with mental fatigue. However, the ongoing Mental Fatigue study at the U.S National Institutes of Health (NIH) may discover some non-modifiable hard-wiring changes relating to the original polio that contribute to brain fatigue. So theoretically, if you have brain fatigue, it is modifiable.

Potentially modifiable factors account for a portion of fatigue in PPS. Dr. Perlman said the presence of these needs to be dealt with to help reduce fatigue. If you deal with stress and depression, then general fatigue scores will improve, theoretically.

Reducing Physical Fatigue

Physical fatigue is the most common symptom and the most disabling in patients with post-polio syndrome. A Spanish study analyzed the effectiveness of various treatments used to improve fatigue syndrome in post-polio patients. They retrieved 396 articles, of which 23 were analyzed in detail. These treatment techniques reduced fatigue in 705 patients.

- lamotrigine (Lamictal)
- bromocriptine (Parlodel)
- aerobics and flexibility exercises
- hydrokinesitherapy
- technical aids

Dr. Perlman suggests that when you pace your physical activity you should be

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able to manage physical fatigue. If you treat the pain, physical fatigue will improve.

Mental Fatigue in Polio Survivors

The study of “Mental Fatigue in Polio Survivors” at NIH examines whether mental impairment is present in PPS patients. If it does exist, how does it interfere with self-functioning of patients?

One of the biggest mysteries in post-polio is problems with slow thinking and memory which seem to go right along with motor difficulties. Is this truly a brain mediated fatigue that affects thinking, learning, etc.? Or does it relate more to psychological or emotional factors?

The term “brain fatigue” is frequently used by patients to express problems in the areas of attention, concentration, memory, and clear thinking. Unfortunately, little is known about cognitive fatigue of PPS patients.

It has been accepted that polio survivors tend not be burdened by psychological baggage that is going to add to their neurologic and physical symptoms. If you happen to have depression it is obviously going to impair you, but it is not directly related to polio.

Polio treatment really needs to be focused on physical and neurologic hardwiring. Many studies have been done trying to sort out what is going on above the anterior horn cell, but there is still no consensus.

Pain

A study in Sweden concluded that pain is common in PPS patients; most patients experienced pain caused by an injury to body tissues. Women have pain more often than men. Older patients experience pain less often than younger patients. Age at time of primary polio infection is important for the development of pain. When neuropathic pain is present, it is important to proceed with a neurological examination to find an adequate diagnosis.

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Orthotics for the Knee

Orthoses play an important role in the therapeutic care of polio survivors. The aim is usually to secure the knee, preventing excessive recurvatum while respecting the patient's own gait.

A study in France by Francis Genet's group concluded:

- Orthoses must be light and pressure-free if they are to be tolerated and therefore effective.
- Some deformities may be helpful for the patients' gait and, therefore, corrections may worsen their gait, especially if a realignment of segments is attempted. It is therefore essential to carefully pre-assess any change brought to the orthoses as well as proper indications for corrective surgery.
- In addition, it is essential for the patient to be monitored by a specialized team.

Impact of Age and Comorbidity on the Progression of Disability

A study from The Netherlands concluded that despite a reduction in muscle strength over a five-year period, the PPS patients' disability level increased little.

- Increased weakness in a quad or in a shoulder muscle really didn't have a significant impact on levels of disability, as measured by disability scales.
- Increased age and the other number of medical factors or surgical problems do have a negative effect on disability.

Predicting which Polio Survivors will Develop PPS

Looking at the long-term ongoing studies, there is probably about a 60 % risk of developing PPS and probably a 40% risk of just living with the original deficits.

In 1995 Post-Polio Health International (PHI), an excellent website and group

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<http://www.post-polio.org/index.html>, established The Research Fund which is dedicated to seeking scientific information leading to eventual amelioration of the consequences of poliomyelitis and/or neuromuscular respiratory diseases.

- In 2007 the fourth PHI award was looking for biomarkers in blood and spinal fluid of polio survivors to see if they could identify a marker that would determine if a person will probably develop post-polio symptoms, or probably not develop them.

How can each group be identified? It has been confirmed that individuals with PPS have higher levels of antibodies and regulatory T cells (which are part of the immune system) circulating in the blood, compared with healthy age-matched controls who never had polio. The immune factors that have been discussed in previous years (tumor necrosis factor Alpha, the interferons, and a few others) are definitely at a higher level in people experiencing active post-polio symptoms.

In this study a cross section was assessed. Stable polio individuals who do not have any new symptomology had variable intermediate levels...a little higher than average, but a little lower than the true post-polio population - not normal but not abnormal.

These easier blood tests are a nice first step that can be built upon. A larger prospective study of stable polio individuals over five years would probably indicate who might develop post-polio symptoms (fatigue, weakness, new atrophy) and who would not. What will happen to their blood tests over that period of time?

- The final report data from the 2009 PHI award indicate that there is a low level of polio virus (PV) protein activity persisting for decades in most polio survivors. The debris is there; it is not infectious, but it is there.

The goal will be to develop a treatment for polio survivors, or survivors of other neurologic infectious illnesses, that may linger and cause problems. Perhaps an effective antibiotic will prevent PPS in the future or prevent progression.

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Conclusion

As PPS research in many areas continues worldwide, we look forward to learning more from Dr. Perlman in May 2011 when she presents research updates and answers personal questions.

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Special Note and Request

The Rancho Los Amigos Post-Polio Support Group and the Post-Polio Support Group of Orange County produce and distribute newsletters on alternate months, using the same shared address list. The printing and mailing of our newsletters is time consuming and personal energy depleting.

Sending the newsletter to you electronically, via e-mail, will reduce costs and help preserve our personal energy level. Many of you have already agreed to this labor saving proposal, and have provided your e-mail address. Thank you. If others would like to add your e-mail address to this effort, please send your name and e-mail address to: keenanwhelan@cox.net

Thank You

Rancho Los Amigos Post-Polio Support Group Meeting Schedule

Saturday, February 26, 2011 - **Annual Potluck**

This is always a fun time.

Please bring something that is easy to prepare, and easy to eat.

*If this is difficult for you, don't worry about it.
There is always an abundant supply of delicious food.*

The support group will supply beverages,
cups, plates, and eating utensils.

Unless notified separately, all meetings are in room 1150 of the Support Services Annex at Rancho Los Amigos National Rehabilitation Center. Meetings are from 2:00p.m. to 4:00p.m. For additional information, please contact:

Diane at 562-861-8128 or Richard at 562-862-4508
or e-mail us at: RanchoPPSG@hotmail.com

Post-Polio Support Group of Orange County Meeting Schedule

Saturday, February 12, 2011- **Assisted Living at Home Care**
with Miguel Ortin of Evergreen Care

Saturday, March 12, 2011 --- Dr Rubinstein *Upper Body Orthopedics*
(TENTATIVE)

Saturday, April 9, 2011 --- MOVIE *The Final Inch* (Polio Eradication)

All meeting are from 2:00p.m. to 4:00p.m. unless notified separately

For information, please call: Marte Fuller 562-697-0507
 Marilyn Andrews 714-839-3121