Founded in 1989

The Post-Polio Support Group of Orange County Newsletter

15231 Marne Circle
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September 2009

Research is our hope for the Future - J. Renison

It is important for all of us to keep abreast of research in the area of Post Polio Syndrome so that we will be able to manage our own disabilities, both on-going and new. I have always been a proponent of such studies and have, personally, participated in several on the assumption that, even if the findings don't help me now, someone in the future could benefit from what was learned. To that end, I am always interested in what Dr. Perlman presents each May wherein she gives a brief synopsis of all the studies done in the past year and what, if any, findings may help us or look promising for future help for us (provided, of course, that we should live so long). I am going to focus this issue, therefore, on Research Studies relative to Polio, beginning with Dr. Perlman's May presentation as well as a number of articles outlining the findings of studies done, either with Post Polio Health International funding or printed in their newsletter. I hope you find it helpful.

Inside this Issue

Dr. Susan Perlman - May Meeting Presentation

While no new research was presented at the Amer. Acad. of Neurology meeting in April, Dr. Perlman felt that the stimulus grants offered by the federal gov't through the NIH would attract new interest in polio research.

Post Polio Health International awarded a $25,000 grant in 2009 to a team in Italy to study residual fragments of Polio and Antiviral Drug Susceptibility. In addition, she mentioned the 2007 award to the Univ of Arkansas for a Pilot Study on Identifying PPS Biomarkers. This study would help to identify those having the PP Syndrome which is currently done by eliinating all other alterternatives. The study number was so small (4 participants) that it would be hard to extrapolate to the general PPS population.

In addition to the research studies, over the past 12 months there have been 20 publications about Post Polio in the medical literature. While these may or may not have included controlled studies, this continuing professional emphasis gives us more information on the potential impact on our independence and what we may do to aid our quality of life. These articles deal with the following areas:

Post-polio Syndrome (2 arts).
Electromyography (2)
Biomarkers (s)
Intravenous Immunoglobulin (1)

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Exercise Treatment (3)
Other general medical Issues (3)
Respiratory/Ventilator Issues (2)
Orthopedic Surgeries (5)

Dr. Perlman explained these articles in some depth. If you were not there to receive the handouts, you might be able to get a copy from her office via e-mail. I suggest it would be worth a call.

In conclusion, she found only one study currently recruiting participants This one deals with mental fatigue associated with PPS.

She also urged everyone to go on-line and register with the John P. Murtha Neuroscience and Pain Institute for polio Survivors. The site is: https"//www.conemaugh.org/apps/postpolio/ There is a 5-10 minute questionaire and any submissions are kept confidential. This registry could be used for finding participants for any future study or clinical trial. ###

$25,000 Grant Awarded to Advance Noninfectious Virus Detection in Polio Survivors

Post-Polio Health Vol 24 #4 Fall 2008

Saint Louis, Missouri – The Research Fund of Post-Polio Health International (PHI) has awarded its fifth grant to a team of researchers from the University of Insubria Medical Center, Varese, Italy, led by Antonio Toniolo, MD, PhD, Professor of Medical Microbiology and Virology. The $25,000 award, funded by PHI's Post-Poliomyelitis Research Grant, is for work to be completed in 2009-2011.

The study, entitled "Persisting Noninfectious Fragments of Poliovirus in PPS Patients: Virus Detection and Susceptibility to Antiviral Drugs," will complete the sequencing of the genome of persistent fragments of poliovirus strains and compare them to wild-type polioviruses. The last year of the study will test the susceptibility of the persistent fragments of polio-virus in vitro to antiviral drugs.

PHI's Board President, Lawrence Becker, PhD, comments, "The application from the team in Italy impressed the panel as having real promise for tracking down the etiology of post-polio syndrome. And if it turns out that these viral fragments play a major causative role, the study will not only help develop an important diagnostic tool, but may point the way toward an effective treatment."

Dr. Toniolo states, "We really appreciated the generous effort of PHI and will certainly do our best to clarify the role of persisting genomic polio-virus fragments in patients hit by polio many decades ago. Our fondest hope is to assess whether newer antivirals may be of any help to the many sufferers of this disabling condition.

We are also particularly proud of conducting part of the study with prestigious investigators of the Columbia University."

Members of the research team include: Dr. Toniolo; Andreina Baj, MD, PhD; Giuseppe Maccari, MS; and Angelo Genoni, BS. Participants for the study will be selected from two clinics that treat post-polio patients – the University of Verona Medical Center, headed by Salvatore Monaco, MD, and the Rehabilitation Hospital "Villa Beretta," Costamasnaga, Italy, headed by Franco Molteni, MD.

"Research funds to specifically study post-polio problems are hard to find," says Joan L. Headley, Executive Director of Post-Polio Health Inter-national. "Generous donations from PHI's Members over the last decade have helped us fill the gap, so research can help answer the questions that affect them in a very personal way. Dr. Toniolo's team wisely has combined the PHI funds with funds

from several other sources. We will update the post-polio community periodically of the progress of the two-year study."

"Amid the international economic crisis and the general shrinkage of research funds, the assignment of the 2008 PHI grant for research on the post-polio syndrome came somehow unexpected to my group."

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Stem Cell Therapy for Post-Polio Syndrome

Post-Polio Health Vol 29 #4 Fall 2003
Edward P. Bollenbach, BA, MA, Professor Emeritus in Biology, Northwestern Connecticut Community College, Winsted, Connecticut

The media is abuzz with talk of stem cells, and there is hope of curing diseases, such as Parkinson's and muscular dystrophy, and spinal cord injury, using stem cell technology. What about polio? It was delightful to see a press release from the Salk Institute this spring, which added post-polio syndrome to the list of targets for stem cell therapy.

A refresher on stem cells

There are two broad types of stem cells with several subtypes:

EMBRYONIC STEM CELLS are derived from the human blastocyst — the result of five days of cell division after sperm and egg fuse into a fertilized egg (zygote).

The human blastocyst is a sphere with about 30 stem cells inside, and these cells have many useful properties for therapy. Prodded with chemical messengers, they can develop into most of the cells of the adult body; i.e., they are luripotent. In a lab dish, they can be maintained, dividing into new stem cells, for more than a year. They could easily be used for production of nerve cells or muscle fibers for post-polio therapy.

However, since the stem cells are not from the patient who will use them, they are easily rejected. This problem can be solved if the stem cells are cloned first by the patient donating a nucleus to a human egg cell and then allowing five days for development until stem cells are evident in the blastocyst. This is called therapeutic cloning or nuclear exchange. Therapeutic cloning requires new legislation and is currently not supported in the United States. Further, embryonic stem cells can transform into cancerous cells easier than the second type of stem cell, or adult stem cells.

ADULT STEM CELLS exist in many parts of the body, such as in the bone marrow, brain, blood, muscle, and internal organs. They are difficult to isolate because, in comparison to the tissue they are within, they represent a very small fraction of cells. However, many adult stem cells are pluripotent and can be prodded to develop into muscle, nerve, skin, and a variety of cell types.

Because the patients can provide the stem cells for their own therapy, the stem cells are not rejected. Adult stem cells are not as prodigious as embryonic cells and cannot be maintained in the lab as long. Theoretically, as the technology progresses, adult stem cells should be able to serve as cellular material for new nerve cells and skeletal muscle fiber.

Some procedures may require embryonic stem cells and others may do better with adult stem cells. In the United States, there are currently very few samples of embryonic stem cells available, which government grants can fund. The American Medical Association (AMA) recently lobbied to have this reconsidered. No news yet.

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Challenge for use in old polio

Old polio presents several challenges that are different from the disorders usually discussed as targets for stem cell therapy. For example, in a spinal cord injury there is a loss of cells at the break in the spinal cord — where the body of nerve cells resides. Outside the cord, each cell projects into a long tube, sometimes three feet or more, which ends at a muscle fiber within a muscle. Theoretically, these long tubes, or axons, end with a few branches that connect to the muscle cells. In a spinal cord injury, these fibers and axons within the peripheral muscles usually remain intact. What needs to be done is to connect a new nerve body with the axon already there. In post-polio syndrome, it is the end branches of the axons that are dying off while the nerve cell itself may continue living or eventually die. If scientists successfully implant new nerve cells in the anterior horn of the spinal cord, can the cells extend axons and connective end branches out through the tissues to a target muscle fiber? In polio, once muscle fibers have lost their nerve connections, they struggle to survive. Muscle fibers typically will atrophy and become non-functional after losing nerve stimulation. Therefore, muscle fibers mayalso need to be replaced. This is much more difficult than implanting new nerve cells in one place such as in Parkinson's disease or spinal cord injury. Yet, there are things that can be done. For example, new nerve cells or support cells can be implanted to either fuse into existing weak motor nerve cells or provide protective chemicals for support.3 This would allow existing motor nerves to function longer and possibly even sprout more. Another approach may be to try to strengthen muscles closer to the spinal cord. Muscles such as the paraspinal or hip muscles, if damaged, can result in more disability than more distant muscles, like the calf. So it may be possible to have a positive impact on muscles at or above the hip, where they cause the most disability if weakened. Regardless, there are several promising approaches, including the use of scaffolding biological materials, such as chondroiten, to guide new nerves to their targets.

Several signaling factors act between stem cells, allowing them to differentiate and grow in the lab or in the body. As stem cell research progresses, more of these growth and differentiation factors for cell specialization, adaptation, and connection should be uncovered.

Looking ahead

Imagine a combination of mechanisms (some of which are already known) that can signal motor neurons (nerve cells) to form connections with new muscle fibers. Muscle signaling cell adhesion molecules (CAM) can attract the placement of nerve synapses (connections) to muscle. Without even using stem cells, new derivative cellular chemicals can guide cells to the proper muscle ibers in a trouble area. There are many other possibilities. The only question is how long will it be until effective therapies emerge from stem cell research. Much of the advancement in stem cell therapies and much of the realization of future promise will come as a result of lab work using model organisms like mice. A model of spinal cord damage, resulting in complete paralysis, has been mitigated in a rat with neurons derived from mouse embryonic stem cells. After treatment, the rat was able to use its hind legs in walking motions whereas prior to treatment it could not.

Rodents can be easily engineered genetically and cloned, without implantedcell rejection. Using a mouse as a polio model (Polio Network News, Vol. 18, No. 4), there is a new

opportunity to study post-polio rehabilitation with stem cells. The possibility of using this polio mouse model for stem cell studies involving polio is clear, due to the success in using rodents to further the understanding of cell differentiation and the possibilities of stem cell therapy.

The most vexing problem for polio survivors may be the speed at which stem cell therapy advancement occurs. The clock is ticking. If rapid advancement in the use of this technology occurs in the next ten years or so, those who had polio in the '40s and '50s may benefit. If not, these polio survivors may just miss the next milestone in medicine — the ability to regenerate muscle and nerve tissue. So close to the remedy, and yet so far.

Edward P. Bollenbach (edward.bollenbach@snet.net) received a BA in Biology and an MA in Biology from the State University of New York at New Paltz, New York. In his professional work, he focused on bacteria and fungi, and, as he began to experience polio's late effects, he decided to use his scientific knowledge to clarify information about post-polio syndrome.

He co-authored an article in 2002 with Marcia Falconer, PhD, Ottawa, Ontario, Canada, "Late functional loss in nonparalytic polio," Am J Phys Med Rehabil, Jan-Feb, 79(1), 19-23.
Sidebar, pg 2

Many polio survivors have weak paraspinal and deep muscles that support the spine, which can be very disabling. The spine is destabilized, resulting in impingement on adjacent nerves, which causes pain and new weakness. Because of their close proximity to the spinal cord, these muscles may be enervated by newly grafted motor neurons. These new ideas in remediation of post-polio syndrome should be considered in the context of stem cell therapy.

EDITOR NOTE:
For current information on human trials of stem cells designed to regenerate spinal motor nuerons see the **June 2009** issue of our newsletter now on our website:

ppsupportoc.org

Post-Polio, Menopause and Aging: 13 Major Study Points Provide New Knowledge, Clues for Care

Post-Polio Health Vol 20 #3 Summer 2004
Sunny Roller, MA, Program Manager, Physical Medicine & Rehabilitation,University of Michigan Health System, Ann Arbor, Michigan (elsol@umich.edu)

The nationwide study is finished and the discussion now begins. During the past year, almost 1,000 postpolio women, ages 34 to 99, openly disclosed their menopause secrets with researchers at the University of Michigan.

What did we learn and what could this information really mean to women who had polio? When I interviewed chief investigator Claire Kalpakjian, PhD, she clarified the essence of the study's thirteen major findings. We also discussed what each point might tell us about how post-polio women could best care for themselves during their well-earned senior years. Each formal study result warrants a slightly closer look, which is accompanied by this author's perspective: feminine, menopausal, pre-retirement and post-polio.

1. Severity of post-polio sequelae was significantly related to severity of menopause symptoms. One of the study's most important questions asked if worse late effects of polio are connected to worse menopausal symptoms. address them with her physician, as a special prevention effort.

2. Greater menopause symptom severity was significantly related to lower emotional well-being. The worse menopause symptoms are, the more likely one will feel a greater amount of stress, have more negative feelings and feel less satisfied with life.

From this, one might surmise that if we can stay on top of the symptoms with our physicians, then we will end up feeling better about

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life in general.

3. Menopause status was associated with severity of post-polio symptoms and physical functioning; agematched men did not significantly differ from women within each menopause status on these outcomes with the exception of late postmenopausal women who reported significantly greater severity of postpolio sequelae than age-matched men. Women who were further along in menopause had more severe postpolio symptoms and more difficulty with activities of daily living than postpolio men their same age. We should seek help for new symptoms. We should take to our physician the brochure, due out soon, that shares the results of this study and discusses the management of polio's late effects.

4. While there were no significant differences by menopause status on emotional well-being outcomes, peri-menopausal women had significantly greater life satisfaction and lower negative affect than age-matched men, and the late postmenopausal women had significantly greater perceived stress than age-matched men. Women approaching menopause were more satisfied with their lives and less unhappy than post-polio men their age. However, women who were at least five years postmenopause were more stressed out than post-polio men the same age. If we know we might tend to be more stressed after we have been through menopause, then we should take what's known about stress management very seriously and read up on techniques or take a class.

5. Despite unknown elevation of risks of use in the context of physical disability, women in this sample used hormone replacement therapy (HRT) at a significantly higher rate than estimates for their nondisabled peers.

Casually stated, more of these postpolio women (39%) were using HRT than their nondisabled sisters across America (23%). We may want to revisit the wisdom of this choice, in light of the new research that has been published in the last year about HRT use.

6. Use of HRT was not associated with better physical functioning or lower post-polio severity nor was it associated with better emotional wellbeing.The bottom line is that using HRT does not help improve polio symptoms, the ability to do things, or how good a woman feels.

7. HRT use did not mitigate severity of post-polio sequelae or physical functioning by menopause status, but late postmenopausal women using HRT had significantly greater severity of post-polio severity and higher basic ADL functioning than age-matched men.

Not only did HRT not alleviate postpolio symptoms, women HRT-users who were more than five years postmenopause actually had worse late effects of polio than post-polio men their same age. This does not necessarily mean that HRT caused the late effects. Also, unexpectedly, despite worse symptoms, the women's ability to do basic self-care tasks was better than the men.

8. Hysterectomy rates among women in this study were significantly higher than the average rate for women in the US. Close to 35% of the post-polio women in this study had had hysterectomies, contrasted to only 21% among American women in general.

9. Age at final menstrual period was average compared to nondisabled women in the US. Both post-polio and nondisabled women across the country had their last period when they were about 50 years old.

10. The experience of menopause among these women was largely positive or neutral. One woman quipped, "Maybe cold polio feet and hot flashes equal out!"

11. Rates of employment of these polio survivors were lower than their similar-aged peers, except for individuals over the age of 65 years who were employed at similar rates as their peers.
12. Middle-aged (45 to 54 years old) polio survivors reported substantially greater perceived stress than their peers in a national probability sample.
Middle-aged polio survivors were more stressed out than nondisabled Americans who were the same age.
Once again, managing stress seems to be highly relevant for us.
13. In general, older participants enjoyed greater positive and lower negative mood and perceived stress. Post-polio people who were 65 and older reported less stress and greater happiness than their younger peers. Good news! Indeed, it is true. We get smarter as we grow older!
Polio survivors in the study appeared to have stopped being part of the national workforce earlier than their fellow Americans. This reminds us that knowing the often intricate details of later life planning (finances, housing, health care, transportation, estate planning, etc.) is especially important if we are likely to retire early. ###

THANK YOU

Special Thank You to the following donors: Don Borchers, Mary Loanne Swenson, Deni Hunter, Betty Thompson and Delbert Catron. It is our policy to thank all donors regardless of amount of donation. All are greatly appreciated.

How to Contact OC Support Group

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Priscilla at PrisofOC@aol.com

How to Contact Rancho Support Group

The Rancho Los Amigos Post-Polio Newsletter is published as a joint venture with the Polio Survivors Association.

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DONATION: Foot Operated “78 Mercury, 55000 miles, Body and Interior in EXCELLENT condition. Dan Holloway will donate this vehicle to someone who has limited or no upper limb use in memory of his late wife, Lee, who drove this car. Contact Dan at: (714) 514-3814

Rancho Los Amigos Meeting

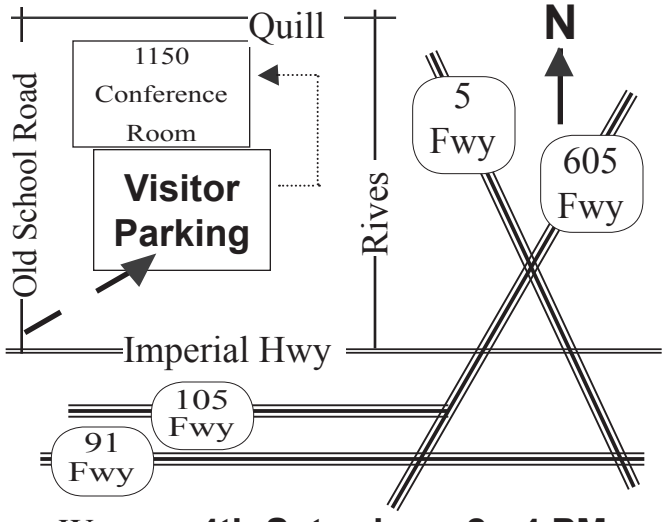
Saturday, Sept. 26

2pm - 4 pm

Future Rancho SG Meetings

Saturday
October 24

Saturday
November 28



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

Orange County Meeting

Saturday, Sept. 12
2 pm -- 4pm

Report from 2009 Post-Polio Int'l Conf
Warm Springs GA

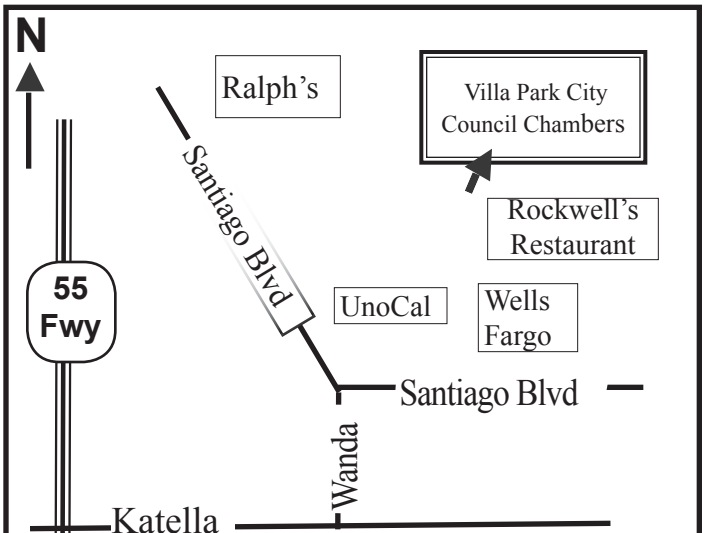
by Baldwin Keenan

Future PPSG of OC Meetings

Saturday October 10
Bracing and Surgery for Polio Survivors
Dr. Stewart Shanfield

Saturday Nov. 14
Medicare 2010
Cliff Roth HICAP

Website: ppsupportoc.org



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