Rancho Los Amigos Post-Polio Support Group

Newsletter - August 2015

A Good Question!

What are the effects of different treatments in people with post-polio syndrome (PPS)?

Many people with post-polio syndrome (PPS) seek an effective treatment that will improve muscle strength, relieve pain, and / or prevent further functional decline. At various times we have read claims about the benefits of certain drugs, supplements, or therapies. In May of this year, the *Cochrane Database of Systematic Reviews*, part of the *Cochrane Library*, reported on research studies of several drugs and treatments.

The Cochrane Library searched scientific databases to find all studies on treatments for PPS up to July 2014. They found thirteen studies involving a total of 675 participants that were of sufficient quality to include in their review. Ten of the studies evaluated the effects of drugs:

Intravenous immunoglobulin (IVIg)
Lamotrigine
Modafinil
Pyridostigmine
Amantadine
Prednisone

Two studies evaluated specific treatments:

Muscle strengthening
Static magnetic fields

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Background

PPS is a condition that can affect polio survivors years after recovery from an initial paralytic attack by the polio virus. PPS is characterized by progressive or new muscle weakness or decreased muscle endurance in muscles that were previously affected by the polio infection. It can also affect muscles that were previously thought to be unaffected.

Other symptoms may include generalized fatigue and pain. These symptoms often lead to a decline in physical functioning in activities of daily living. The objective of this Cochrane review was to assess the benefits and harms of different drugs and rehabilitation treatments compared to placebo, usual care, or no treatment.

Key results and quality of the evidence

IVIg is a treatment in which antibodies that have been purified from donated blood are given as an infusion into a vein over a period of time. There was moderate and low-quality evidence that IVIg has no beneficial effect on activity limitations in the short term or long term.

Evidence for effectiveness on muscle strength after using IVIg infusions was inconsistent, as results differed across studies. IVIg caused minor side effects in a substantial proportion of the participants.

Lamotrigine is a drug used to help control certain kinds of epilepsy and to treat bipolar psychiatric disorder. Results of one trial provided very low-quality evidence that lamotrigine might be effective in reducing pain and fatigue, resulting in fewer activity limitations and, in this study, it was well-tolerated. These conclusions were based on one small trial with limitations in study design.

There was evidence varying from very low quality to high quality that the drugs modafinil, pyridostigmine, amantadine, and prednisone are not beneficial in PPS.

There was very low-quality evidence that strengthening of thumb muscles can be safe and beneficial for improving muscle strength. They based these conclusions on results of only one small trial with important limitations in study design, and they are applicable only to thumb muscles.

Static magnetic fields is a therapy in which electrical currents are applied to the skin with the intention of reducing pain. There was moderate quality evidence that static magnetic fields are safe and beneficial for reducing pain directly after treatment, although functional effects on

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activities of daily livings and adverse long-term effects are unknown. You can find the complete review at:

http://www.cochrane.org/CD007818/NEUROMUSC_treatment-for-postpolio-syndrome

In addition, when discussing magnetic therapies, a review by the journal *Evidence Based Complementary and Alternative Medicine* stated, "Complete descriptions of the static magnetic force (SMF) dose that was applied to human participants are notably lacking in the majority of SMF therapy studies published to date. Without knowing the SMF dose that was delivered to the target tissue, we cannot draw meaningful inferences from clinical trial results. As research on SMF therapy progresses, engineers, physicists, and clinicians need to work together to optimize SMF dosage and treatment parameters for each clinical condition. This report can be viewed at:

http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2686626/

WELCOME

We, in the Rancho Los Amigos Post-Polio Support Group, have been fortunate and privileged to welcome several new attendees and welcome back some of those who have been unable to attend. Our July meeting was excellent. We began as we usually do with introductions, allowing each person to tell about their polio history. At this meeting the introductions began an exchange of personal stories with questions and answers. This is what a support group does best.

According to the dictionary, a support group is, "a group of people with common experiences and concerns who provide emotional and moral support for one another." We believe a support group is this and more. We don't just provide emotional and moral support. We also provide accurate information, helpful ideas, and lots of fun.

The Rancho Los Amigos Post-Polio Support Group meets the fourth Saturday of each month, except as noted in the meeting notices. We encourage family members and friends to attend meetings.

On the next page is an article that first appeared in 1999. It tells how the polio support movement began.

Where Did We Come From?

by Richard Daggett, President, Polio Survivors Association

First printed in a 1999 issue of the Rancho Los Amigos Post-Polio Support Group newsletter

No, this is not an article about the birds and the bees. It is a story of how the polio support group movement began. As the Rancho Los Amigos Post-Polio Support Group enters its twelfth year (now, in 2015, twenty-eighth year) it seemed a logical time to reflect on where we are and how we got here.

In the beginning there was Gini Laurie. No history of the polio support group movement could begin without mentioning Gini. She is described as "the glue that held the polios together." Gini lost two sisters and a brother to polio, and another sister contracted polio but survived. Her early involvement started as a volunteer at the Toomey Respiratory Pavilion in Cleveland, Ohio. In 1958 she began publishing the Toomey J. Gazette, which evolved into the Rehabilitation Gazette*. Through this publication, and her correspondence with polio survivors, people with other disabilities, medical professionals, and independent living advocates, she began a network that was instrumental in identifying the problems we now face.

* This evolved into the publications of Post-Polio Health International www.post-polio.org

Gini Laurie was a vigorous advocate for people with disabilities. She encouraged us to be pro-active, seeking solutions to whatever problems we encountered. In 1974 a group of polio out-patients of Rancho Los Amigos Medical Center were discussing some of their common concerns. Among these were how to remain independent in their own homes, and how to obtain and maintain adaptive equipment necessary for their independence. This group of polio out-patients decided to organize as the Polio Survivors Association and, in 1975, formed a non-profit corporation to promote the well-being and improve the quality of life for severely disabled polio survivors. Few people knew about the late effects of polio, or what we now call post-polio syndrome. The Polio Survivors Association was the first organized polio support group.

In 1981, Gini Laurie planned and coordinated the first large conference dealing with the late effects of polio and living independently with a disability. Among the questions posed at this conference were, "What's happening to so many of the polio survivors, and why are they experiencing renewed fatigue and weakness?" No definitive answer came out of this conference, but it began to focus our attention. On this issue Polio survivors and those health professionals who had been working with them initiated the first preliminary studies.

At the second international conference in 1983, in St. Louis and again organized by Gini, the

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term “post-polio syndrome” was used by some of the speakers. It was sometimes mentioned in a questioning manner. Was there really something here, or are we overreacting? The CBS *Sunday Morning* news program with Charles Kuralt taped part of the conference. When this aired on the nation’s television sets it turned a spotlight on the problem. There was no turning back. In 1984, Gini Laurie and Judith Raymond, in collaboration with Drs. D. Armin Fisher and Frederick Maynard, published the *Handbook on the Late Effects of Polio for Physicians and Survivors*.

April 12th, 1985, was the 30th Anniversary of the Salk polio vaccine. Almost all of the news coverage of this historical event included mention of polio’s late effects. By then several additional post-polio support groups had begun. These were mostly local or regional groups, but their newsletters helped spread the word beyond their borders. The original Polio Survivors Association started focusing more of its efforts toward educating polio survivors, their physicians, and the general public about this growing problem.

A small, barely two paragraph article titled “*The Polio Scare Returns*” in the July 1986 issue of *Family Circle* magazine indicated a developing concern. Over 3,000 letters in response to this article were sent to the Polio Survivors Association. Some individuals told of problems they were already experiencing, but didn’t understand. Some expressed frustration with the medical community. And others were worried about the future.

The Rancho Los Amigos Post-Polio Support Group was formed in 1987. Rancho was the largest respiratory polio center in the United States and continued to see many polio survivors in its out-patient clinics. Drs. Jacquelin Perry and D. Armin Fischer of Rancho were among the first to recognize the late effects of polio and publish articles in prominent medical journals. Dr. Perry asked permission of the Polio Survivors Association to use their mailing list to contact individuals who might be interested in forming a local support group.

Early estimates of the number of polio survivors were between 250,000 and 300,000, with about 25% of these at risk. As more information became available these numbers increased. Current estimates are that 1.6 million individuals in the United States were diagnosed with polio, and about 600,000 were left with some identifiable residual paralysis ranging from barely noticeable to severe. More than 50% are experiencing problems or may be at risk.

Polio survivors are often categorized as having “Type A personalities.” Whether this is true or not, we seem to be very pro-active. No other large disability group has been as passionate about finding the cause or causes of our problems, or as eager to find and educate our health professionals. Probably no other disability has produced more support groups or published more newsletters and informational material.

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Where did we come from? We came out of the dedicated efforts of advocates like Gini Laurie, Judith Raymond Fischer, and Joan Headley. We were fortunate to have the vision of polio survivors like Renah Shnaider, Harriet Bell, Nancy Baldwin Carter, and those who founded the Polio Survivors Association. We were supported by health professionals like Jacquelin Perry, Armin Fischer, Frederick Maynard, Augusta Alba, Stanley Yarnell, and Lauro Halstead. And we've been sustained by those who contributed their time and talents to help others learn to accept change and develop new coping styles. We owe a great deal to so many, and we give each of them our thanks.

Meeting Notices

Rancho Los Amigos Post-Polio Support Group:

Saturday, August 22, 2015 - 2 p.m. to 4 p.m. - Continuing our series of programs about preparing for future needs.

For additional information, please call Diane at (562) 861-8128

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Post-Polio Support Group of Orange County:

Saturday, September 12, 2015 - 2 p.m. to 4 p.m. - To Be Announced

For information Contact Marilyn at (714) 839-3121 or prisofoc@aol.com

Please remember, both groups encourage your family and friends to join you at our meetings.