



The Polio Post

The Voice of the Polio Survivors & Associates Fellowship

(A group of Rotarians dedicated to improving the health of polio survivors. This Fellowship operates in accordance with Rotary International policy, but is not controlled by Rotary International.)

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New Editor

Hello, I am Jack Campbell, a Rotarian from the Escondido Rotary Club in California and a polio survivor for the last 56 years. Ray Taylor, the current chairman of our Fellowship, has gotten too busy to do everything and has asked me to be the new editor of The Polio Post.

With this issue you will see the beginning of some new formats and methods of distribution. I hope you will like them.

Please help me by giving suggestions for material or new subjects or criticism of our efforts.

You can email me at: Jackcampbell@cox.net.

Methods of Communication

Our primary means of communication are two fold.

1) The Polio Survivors & Associates Fellowship has a website, <http://www.rotarypoliosurvivors.org/> The website contains archives of our newsletters, including a mission statement in Issue #4.

2) We maintain an email list and use it to occasionally send information to anyone who subscribes. To subscribe go to:

<https://www.taranto.com/mailman/listinfo/psa>.

You may also send a message to the group moderator for posting to the group by sending an email to psa@taranto.com. You may be requesting advice or informing the members of an upcoming event or new research or describing an experience you have had.

All emails will be reviewed. Messages are not automatically forwarded to everyone, but when appropriate they will be. For specific questions, we will forward it to appropriate professionals that might be able to help.

Members are mailed a message with the link to any new newsletters or other additions to the website when they are available. Everything is stored as a PDF file.

The purpose of The Polio Post continues to be a tool to help Rotarians help the Polio Survivors of the world. There may be as many as 2,000,000 in the USA alone. They once thought they had survived polio and could now go on with the rest of their lives. Unfortunately, 15 to 40 years later something is causing weakness to very slowly return in many of the survivors. It is our Fellowships goal to help them and ourselves.

Rotarians around the world are working very hard to end new polio cases by next year. My wish is that polio dies before I do. Meanwhile, many good Rotarians and doctors are trying to also help the polio survivors.

Page 2 this month is a reprint of an article from **Jacquelin Perry, M.D.**, Dr. Perry was in charge of the Rancho Los Amigos National Rehabilitation Center, Polio and Gait Clinic, from 1971 and has one of their institutes named after her. She is a world renowned expert on treating post polio patients.

General Information for Post Polio Patients

Why are old polio patients who were stable for years now losing function? What can they do about it?

The basic problem is polio destroyed some of the nerve cells which activate the muscles. To the extent possible, the neurological system responded by having the remaining nerves adopt the muscle fibers which had lost their original nerve supply. This meant that the nerve cells now had a demand much greater than normal. While, this was an effective solution initially, the passage of time (30+ years usually) has taught us that overuse can be destructive. As a result, these secondary nerve cells are wearing out with resulting muscle loss, i.e., the Post Polio Syndrome.

The apparent abrupt loss in function relates to two functions. One is the buffer zone present in all our physiological systems which enables them to accept strain for a considerable period of time, but once the buffer limits are exceeded the loss is very prominent. Secondly, activities such as walking or lifting objects present fixed mechanical demands. As long as the person's muscle strength exceeds that demand, he/she can continue to perform as usual, but with earlier fatigue. When the strength goes below the essential limit suddenly that function is lost.

The answer is to redesign your lifestyle to avoid those activities which cause muscle strain, cramping, persistent fatigue and consequently weakening. This means to very carefully look at how you are using your arms, legs, back and avoid those tasks that cause the symptoms of persistent fatigue, muscle soreness and/or a sense of weakness after use. At times, this requires the employment of special devices to take the load off the arms. If the changes are made early, strength can be recovered. It will not be sufficient to prepare the muscles for excessive strain again, but it does bring the muscles up to a more useful level. Other ways of reducing strain is by using self-care devices, walking aids, braces and corrective surgery to lessen the stress.

Once the strain has been reduced then cautious exercise may be of value. We have been using short duration (5 repetitions) or moderate intensity (50% - 75% of ones maximum capability). Let me caution you not to take on the exercises, however, until you have worked out a lifestyle that avoids the strain. Also, if the exercises cause any pain, persistent fatigue or increased weakness, **STOP!** This means just the mechanical activities of daily living (ADL) are sufficient exercise for your muscles.

Recent research on the course of muscle strength over time in persons over 50 years of age showed a normal average decline of 1% per year, but for post-polio survivors the rate was 2% per year. The rate of change was so subtle that a four year study was needed for a measurable change. Also, the weaker polios experienced greater functional loss. This latter fact appeared to indicate strength training by exercise would defer the process. However, retesting this group of polio survivors at 8-years and adding muscle analysis told a different story. The muscle fibers were hypertrophied, twice normal size, not atrophic. The person with the greatest strength loss also had the greatest hypertrophy. MRI recordings showed areas of muscle loss and fatty replacement. Hence, the source of the visible muscle atrophy is muscle fiber loss secondary to nerve fiber overuse and failure. These findings confirm the need for a saving program rather than challenging exercise.

The advantage of having had poliomyelitis rather than some other disability is that it allowed one to resume very active and profitable lives for many years. Now it is necessary to recognize that excessive strain was being experienced and that lifestyles must be changed to accommodate this situation.

Be an "Intelligent Hypochondriac" - Listen to your body and adopt a program which avoids the strain.

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