



Newsletter

A QUARTERLY UPDATE FOR NEW JERSEY POLIO SURVIVORS

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Dr Maynard Outlines PPS Exercise Criteria at PNNJ Conference *by Ruth Wyler Plaut*

“The Role of Exercise in Post-Polio Health” was the topic chosen by Frederick M Maynard, MD, of Marquette, Mich., for the 18th annual meeting of the Polio Network of New Jersey held on April 13, 2008, at the Bridgewater Marriott Hotel. Dr Maynard emphasized that exercise plus the activity of moving around during the course of the day contributes to our overall health and wellness. For a holistic view of health and wellness, he asked us to think of a triangle formed of body – mind – spirit. Our body works best when all three elements are in tune. In addition our body needs good nutrition, adequate rest and sleep, as well as exercise and daily activity.

There has been a great deal of controversy over the role of exercise for post-polio patients. Is it good or bad? What types of exercise and what degree of intensity are appropriate? What methods should be used? Which muscles should be exercised? What if you have post-polio syndrome (PPS)? At this stage of life many who have had polio also need to separate the effects of aging from those of neuromuscular disability.

Dr Maynard, who has had extensive experience treating post-polio patients, believes there is value in exercise. The devil is in the details! He noted three types of exercise for the body: planned exercise that consists of structured, repetitive body moves; the physical activity that occurs during the course of our daily activities; and therapeutic exercise that is done for a specific purpose. Common sense tells us that inactivity leads to weakness and de-conditioning and over-exercising leads to injury, pain, and overuse weakness. Polio survivors are rather prone to the latter. Polio survivors who over-exercise can require as much as seven-times longer to regain strength. The important fact is that exercise done properly can help.

Value of exercise

Exercise accomplishes a number of things. It helps to maintain our flexibility, our strength, and our conditioning or endurance. Flexibility exercises are done to maintain the optimal length of a muscle. To accomplish this, a muscle is stretched to the point of tightness and held in position for a few

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New Knowledge and Innovative Remedies Form Theme for 18th Conference

The 18th Annual Conference on the Late Effects of Polio, sponsored by the Polio Network of New Jersey, and held at the Bridgewater Marriott Hotel on April 13, featured talks by two internationally known experts on PPS.

Frederick M Maynard, MD, specialist in physical medicine and rehabilitation at Marquette (Mich) Medical Center, spoke about the ever-controversial topic of the role of exercise for post-polio patients. A thorough report of his talk appears in this issue. Joan L Headley, Executive Director, Post-Polio Health International (PHI), in St. Louis, Missouri, brought attendees up to date on “What’s New in Our Post-Polio World?” A report of her talk will be included in a future issue of the *Newsletter*.

Three afternoon workshops

A trio of workshops was held in the afternoon. “A Polio Survivor’s Guide to Balance and Swallowing” was led by S. Thomas Westerman, MD, of Shrewsbury, a specialist in otolaryngology. “Making Your Home Accessible” was presented by Jack Purvis, AIA, architect from Allenwood. “Chasing Stress with Chair Yoga” was led by Marie Gagliardi, a Yoga teacher from Maywood. Reports on these workshops will also be included in future newsletters.

Dozen exhibitors

A variety of exhibitors were on hand representing companies and organizations that provide products

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Wellness Retreat for Polio Survivors

Bay Cliff Health Camp, set on Lake Superior in the Upper Peninsula of Michigan, is a unique therapy and outdoor recreational facility for hosting health, wellness, and educational programs for children and adults with physical disabilities. The goals of its program are to increase independence and enhance the ability to live a fuller life.

This fall Bay Cliff will host its 3rd annual Post-Polio Wellness Retreat from September 22 through 27. The retreat will offer a week of recreational and therapy sessions for polio survivors. Dr Frederick Maynard is the Medical Director. Applications for the September session may now be filed.

For more information, write
Bay Cliff Health Camp
PO Box 310
Big Bay, MI 49808
phone 906-345-9314
www.baycliff.org
or e-mail, baycliffhc@aol.com.

PPS Exercise

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moments. Stretching is important in pain management; however, it is important to avoid over-stretching of elongated or weak muscles. Stretching is also important for maintaining as full a range of motion of joints as possible.

There are a number of types of strengthening exercises for muscles and joints. There are isotonic exercises in which the muscle is shortened; isometric exercises in which a muscle does not move against a joint; isokinetic exercises in which the force required remains the same throughout the motion (this type is usually done at a facility or using a machine); concentric exercises in which the body requires an increasing amount of strength to perform; and eccentric exercises in which the body requires decreasing amounts of strength to perform.

The key principles of strengthening exercises are, if using "low" resistance, to start with 5 to 8 repetitions; if using use "high" resistance – 60% of 3 repetitions maximum. In all 2 cases, advance slowly, by at most 2 repetitions every 3 to 4 days. Dr Maynard recommends following Dr Jacqueline Perry's Rule – If pain or fatigue occur, reduce by one-half.

If a patient's fatigue threshold during exercise is reduced by less than 16%, continuous use of the muscles is possible. If a reduction of 37% is noted a 50/50 rest/activity balance is desirable. If the threshold is reduced by 70%, a 90/10 rest/activity balance is recommended.

Strengthening muscles

The muscles to target for strengthening are those for which there is an achievable therapeutic goal. Using the 5-point classification system of Dr Lauro Halstead, muscles classified as I (no clinical evidence of polio and negative findings in electromyogram (EMG) and II (sub-clinical polio, benign EMG) can be treated normally. However, for types III (clinically stable, EMG findings and chronic weakness); IV (clinically unstable, new weakness and EMG concerns); and V (clinically severe, atrophic polio), it is necessary to proceed with care in exercising.

Methods for strengthening include the use of free weights, therabands,

machines (need professional advice for these), moving one's body weight, and targeted movements. With each of these there is real value in having a professional trainer plan a suitable exercise regimen.

The third reason for exercising is to improve conditioning or endurance. To increase the endurance of specific muscles, it is necessary to do many repetitions but at low resistance. The measure of the endurance of the whole body is the Target Heart Rate. A lower (desirable) Target Rate is achieved by gradually lengthening the exercise time. For post-polio patients the key to conditioning exercises is interval training. Aim for a 20% minimum break time initially, then go to shorter break times. If there is evidence of heart disease, exercising should be monitored at the beginning. Cardiac training programs are excellent for polio survivors.

Improving conditioning

Some of the ways of exercising to improve conditioning or endurance include: walking or using a treadmill; a stationary bike, a rowing machine or a Tru-step machine; an elliptical machine (not too many polio survivors can use these); an aerodyne bike; an arm ergometer; and free weights or one's body weight. To reach one's goal, 3 to 4 training bouts weekly are needed. To maintain the gain, 2 to 3 training bouts weekly are needed.

In considering exercise and PPS, we need to realize there is no universal definition of PPS; it is a diagnosis of exclusion. In planning an exercise regimen, activity and exercise habits before any new weakness was noted must be honestly described. Stress, general health, and lifestyle all come into play in determining the cause of a weakness. One must make sure the perception of one's current state is accurate and not that of several years ago. There are a number of factors that affect the perception of loss of strength. Many are unaware of the actual strength loss from their acute polio.

The aging process eventually has an effect, so does weight gain. Poor nutritional habits must be considered. Under-activity or de-conditioning contributes to loss of strength, but on the opposite side of the scale, overactivity or overuse do, too. Lastly

poor pacing with inadequate rest periods can have a negative effect.

The approach to exercise for people with PPS is the same as for other people but it requires a more careful and limited approach. Dr. Maynard suggests starting off at a maximum of 30% of usual demands.

Water exercise excellent

Water exercises are a superb way of improving both flexibility and endurance. The challenges in the use of water exercises for polio survivors are the temperature of the water (needs to be warm); the ease of getting in and out of the pool; and overall safety for the individual.

The Polio Health International (PHI) Task Force recommendations on exercise are based on the belief that individualized exercise programs can enhance the health and functional activity tolerance of polio survivors. These programs are best designed and supervised by professionals with knowledge of PPS. A minimum of two months is recommended before one should move to a self-directed program. Exercise programs need to follow the general principles of low-to-moderate intensity, slow progression, and pacing. It helps to consider rotating the type of exercise as well as scheduling less frequent bouts. One needs to allow a longer duration of time to achieve goals, weeks even months.

Pain and exercise

Of note, pain and exercise are often intertwined. There is a vicious cycle of pain leading to disuse that leads to weakness that produces pain again. In considering pain one needs to determine if it is muscle pain or joint pain. Muscle pain occurring with daily activities may require some modestly painful strengthening exercises to relieve. A fear-avoidant attitude toward pain and activity is a major problem in the US population, even among healthy, young people.

The pain associated with the acute and chronic stress-and-strain syndrome can be caused by a variety of things such as muscles, tendons, myofascial areas, joints, ligaments, the spine and its discs, peripheral nerves, and whole body stress disorders. However, nothing ventured, nothing gained. We need to be

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honest and timely in our communication with the professional staff involved with our training. As to the use of adaptive equipment, Dr Maynard recommends exploring the various types before we have to use any. Some devices may solve one problem but create others. Goals for their use are essential.

In conclusion, exercise can enable some muscles to improve strength and/or endurance. Some post-polio people can improve fitness. Interval training and pacing are essential to a successful regimen. We should have clear goals for what we hope to accomplish with exercise.

The Community Foundation of New Jersey Awards Grant to PNNJ

The Community Foundation of New Jersey, an independent, family-created philanthropic agency, has awarded \$2,000 to the Polio Network of New Jersey. The funds, made possible through the generosity of the George A Ohl Jr Fund, will be used to augment PNNJ's own Ruprecht Fund, established by our network in the year 2000 to give direct assistance to New Jersey polio survivors.

The Community Foundation of New Jersey supports a variety of worthy causes; its website describes the foundation as "built for consistent, responsive, and timely giving. On an ongoing basis, community needs are assessed and projects are selected based on where our resources can deliver the best outcomes."

The Ruprecht Fund was established in memory of Alan and Peggy Ruprecht, founders of Drive-Master, Inc, of Fairfield, New Jersey. Alan, a polio survivor himself, was well known to many hundreds of people with disabilities in New Jersey, not only for providing them with "wheels" and hand controls over many years, but for his service to the community.

Since 2001, PNNJ has awarded 44 grants totaling more than \$14,000 to New Jersey residents. This amount has

LegalEase...

by Arthur P Siegfried, Esq

The United States has been found to discriminate against blind or partly blind persons by making paper money all the same size and texture. This ruling came in a Federal Appeals Court decision recently handed down and has been appealed to the United States Supreme Court.

If this decision stands, the Treasury Department may have to redesign our paper money, and vending machines may need to be refitted to accommodate new currency. This issue will become more pronounced as the number of blind or partly blind persons is expected to double in the next 20 years or so because of an aging population and the prevalence of diabetes. The current decision certainly goes a long way in showing that the rights of the partly or totally blind person are being recognized.

This case was reported in the May 22 newspapers. My personal opinion is that (1) an appeal will be taken and that the United States Supreme Court will grant the right to be heard, and (2) we will eventually have a final decision of our court system on this issue.

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been generated entirely through the generosity of members and friends of our Network. The gift of the Community Foundation of New Jersey comes at a most timely moment, enabling us to ensure that we can continue our goal of dispensing up to \$5,000 each year to applicants who meet our criteria for a wide range of polio-related needs. Grants to individuals may not exceed \$500 in any one fiscal year. Those interested should call or e-mail the administrator of the Ruprecht Fund, Heightened Independence & Progress (hip), a Center for Independent Living (CIL) located in Hackensack; for an application form, speak to Maria Valentin at 201-996-9100 or e-mail to mvalentin.ber@hipcil.org.

Those interested in learning more about the Community Foundation of New Jersey will find their website informative: www.cfnj.org.

New Support Group Starting

The Network is delighted to announce that the new Essex-Union Polio Support Group will hold its first meeting on September 13, from 12 noon until 2 pm, at the East Pavilion of East Orange General Hospital. For more information, contact group leader Edwina Jackson at 973-673-0380 or nubianqueen8@aol.com.

Post-Polio Health International (PHI) invites us to Warm Springs, Georgia, for the 10th gathering of the post-polio community coordinated by PHI.

The extensive program will provide polio survivors tools to live well with the late effects of polio; offer a forum for the exchange of ideas among survivors, families, and health care professionals; and explore the history and legacy of the polio epidemics and its survivors. The conference is scheduled to begin at 1 pm on Thursday, April 23, 2009. The final educational session will end at 4 pm on Saturday, April 25, but there will be a social event on Saturday evening.

Interested in a pre-conference retreat that will go one step beyond re-rehabilitation and focus on health and wellness? A Post-Polio Wellness Retreat is being planned for Sunday, April 18, - Thursday, April 23, 2009, modeled after the popular retreats held at Bay Cliff Health Camp in Big Bay, Michigan. Want to know more? Watch the 10-minute DVD "Holistic Health and Wellness Retreat for Polio Survivors," available through PHI.

Hotel accommodations will vary in cost and luxury. Watch www.post-polio.org for details. You may also call or write PHI in St Louis at 4207 Lindell Blvd, #110, St. Louis, MO 63108-2930. Phone: 314-534-0475.

18th Conference

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and services to people with mobility and respiratory limitations. Ample time was provided in the day's program for attendees to visit with exhibitors and learn about their offerings. A popular demonstration was given by Independence Technologies, maker of the stair-climbing iBot power chair.

Special thanks to the New Jersey Chapter, March of Dimes Birth Defects Foundation (Central Jersey, North Jersey, and South Jersey Divisions) for their generous support of the conference.

“Women Aging with Polio” Results Reported

The School of Nursing at the University of Texas at Austin has completed their research on women aging with polio, and they have issued the following report of their data.

“When we looked at the data, we felt it demonstrated the complexity of women's lives as they age with polio. We found that the degrees of functional limitation did not significantly predict how satisfied women were with how they were treated as women. Valuing both the giving and receiving of help to and from others and welcoming information from others about changes in their health did predict satisfaction with how they were treated as women. This indicates that women's satisfaction with the way they are treated has less to do with their perceived level of function and more to do with the way they process the way they are treated in their interpersonal relationships.

“This data also supported the assertion that the frequency of pushing to endure pain and fatigue to remain active predicted the number of other illnesses reported besides polio. Pushing to endure pain and fatigue also predicted more ability to fulfill important social roles. This indicated that women

with polio may push themselves past comfort levels in order to do more things in their lives that are important to them but by doing this they may

Tuning in on the Polio Network of NJ

ATLANTIC COUNTY AREA

May's Landing Library
Farragut Avenue
May's Landing
3rd Saturday, 10 am-12 noon
Contact: Marge or Steve Disbrow
For directions and to confirm date
609-909-1518

BERGEN COUNTY

Maywood Senior Center
Duvier Place
Maywood
1st Saturday, 10:30 am-12:30 pm
Contact: Heather Broad 201-845-6317

MONMOUTH COUNTY AREA

Seabrook Village
300 Essex Road
Tinton Falls
3rd Monday at 2 pm
Contact: Toni Wilczewski 732-229-9343

MORRIS COUNTY AREA

March, July, Aug. & Dec
Zeris Inn
Route 46 East, Mountain Lakes
3rd Wednesday at 7 pm
All other months
Denville Municipal Building
1 St. Mary's Place
3rd Saturday at 11 am
Contact: Marion Rosenstein 201-585-8125
or Vince Avantagiato 973-769-0075

OCEAN COUNTY AREA

Health South Rehabilitation Hospital
of Toms River
14 Hospital Drive
Toms River
3rd Saturday, 10 am-1 pm or 11 am-2 pm
April, September, and November
Contact and confirm date and time with:
Susan Payne Gato 732-864-0998 or
Kevin Marie Moore 732-240-4272

RARITAN VALLEY— Somerset/Hunterdon Counties

Manville Library
Manville, 908-722-9722
1st Saturday, 10 am-12 noon
Oct, Nov, Dec, March, April
Contact: Arthur Siegfried 908-722-7212
Fax: 908-429-1045

SOUTHWEST JERSEY AREA

New Seasons at Voorhees
501 Laurel Oak Road
Voorhees
4th Saturday, 10:30 am-12 noon
Contact: Anna Nasuti 856-740-1106

As meeting locations, days, and times may change, it is advisable for those who are not in frequent touch with support groups to call the contact persons in advance of your planned attendance.

increase the likelihood that they develop further problems beyond the initial reason for their functional impairment, which was polio. The most common illnesses reported were wear and tear and stress-related illness such as osteoarthritis, back pain, and high blood pressure. Further research is needed to be able to test these findings over time.”

Tom Wilczewski Wins Art Awards

Tom Wilczewski has won the “Special Judges Award” from the New Jersey Chapter of the American Artists Professional League. He has also won first place in watercolor at both the Art Society of Monmouth County's Ruth Crown Memorial Art Show and the Princeton Medical Center Art Show. He is an associate member of the NJ Watercolor Society.

Tom is editor of the Monmouth County polio group's newsletter and a former member of the PNNJ Board of Directors.

*Have a Happy
and
Safe Summer*

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Polio Network of New Jersey NEWSLETTER

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