

# POLIO NETWORK NEWS

## Aspects of Muscle Compensatory Processes and Physical Activity in the Survivors of Polio

*Gunnar Grimby, Professor of Rehabilitation Medicine, Göteborg University, Göteborg, Sweden*

With the increasing understanding of the factors causing new symptoms in polio survivors comes an increasing awareness of the benefits and risks of physical exercise and training. Some training studies have been reported lately in the literature that can be of help in recommending appropriate training regimes. An important aspect is that different muscles in different persons can be very differently affected by polio: some may be atrophied to the point where no exercise or training is possible; some may be moderately weak but in an unstable state showing progressive weakness and a risk for overuse; others may be moderately weak but stable to where some training might be of value; and in some muscles, compensation by reinnervation has resulted in "nearly normal" or "normal" muscle function, but there might be risk for disuse. It is, thus, important to individualize the training advice, not only among individuals but also for different muscle groups of a particular individual.

In practice, this is a great challenge to the physiotherapist, and other professionals who design the training programs, and requires a detailed analysis of the muscle function both with clinical testing and laboratory investigation using dynamometer measurements and electromyography. Our experience is that by having detailed information, the polio survivor has a better opportunity to adopt a daily physical activity pattern that provides the appropriate amount and type of exercise but without overuse and fatigue.

### **DOES TOO MUCH DAILY PHYSICAL ACTIVITY AND EXERCISE TRAINING CAUSE ACUTE AND/OR PERSISTENT DAMAGE OF POLIO-AFFECTED MUSCLES?**

To answer this question, detailed knowledge about the compensatory processes in the polio-affected muscles is necessary. Compensation occurs through reinnervation by adjacent nerve fibers to muscle fibers (muscle cells), which have lost their innervation by the death of nerve cells in the acute polio phase as well as later on. The polio-affected muscles otherwise would have atrophied. This compensatory mechanism seems to be very powerful: a nerve cell can reinnervate 4-5 times the normal number of muscle fibers and, in extreme cases, even more than 10 times. The other compensatory mechanism is hypertrophy of the muscle fibers, most likely caused by extreme use of the weak muscle that is still strong enough to be used in daily activities. Even to rise from a chair or walk on a flat surface may give a near maximal load and by that be a stimulus for increase in size of muscle fibers, but not in number, just as in very heavy resistance training. Muscle fibers may then reach a size double or three times the normal size. Thus, whereas physical activity does not seem to be a prerequisite for reinnervation, it is for the increase of muscle fiber size.

**IS THERE A DANGER IN HAVING LARGE MOTOR UNITS (THAT IS, TOO MANY MUSCLE FIBERS INNERVATED FROM THE SAME NERVE CELL) AND TOO LARGE MUSCLE FIBERS?** Our recent follow-up studies over eight years (Grimby et al, 1998) indicate that very large motor units, more than 20 times

normal, with around 10 times the normal number of muscle fibers, may have problems. Either they may lose some of their muscle fibers and thin out due to defective neuromuscular connections, or they may just die easier. We have no systematic information available whether physical activity and overuse could bring about such a loss of muscle fibers or nerve cells. A defective neuromuscular transmission can be identified in some motor units, but we have not found in our studies an indication that this is a major factor for muscle weakness. Whether it can contribute to muscle fatigue is still under debate. The other compensatory mechanism — hypertrophy (increase in size) of muscle fibers — has a positive effect on the maintenance of strength, but it could be a negative for endurance, as capillarization and the aerobic metabolic system of the muscle cell (mitochondria) do not increase in response to the increase in size. Indeed, such large muscle fibers may be less resistant to overuse.

We know, in fact, very little about the risk of overuse causing persistent muscle damage. What we know now is the risk for long-lasting fatigue after too strenuous exercise in polio-

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affected muscles. They need a longer recovery period than "normal" muscles, which must be taken into account when designing training programs and adjusting daily activities. In training studies, we have the experience that with long enough rest periods, which could be days or weeks after a too strenuous bout of exercise (Agre et al, 1998), full recovery will occur. Thus, there is a risk for overuse but, with proper attention to the fatiguing symptoms, the function will recover after the exertion. The risk occurs when the polio survivor does not rest enough, and his/her muscles remain in a constant condition of overload, with its negative effects on function. Although this is not easy to prove scientifically and experimental studies would be unethical, we must rely on a successive collection of data to understand the balance between the pros and cons of physical activity. My personal view is that an approach of trial and error under professional monitoring will yield in practical terms what is a beneficial level of physical activity and what could be deleterious for a specific individual.

**THE LITERATURE NOW DOCUMENTS A NUMBER OF TRAINING STUDIES.** Of prime importance is separating resistance from endurance training programs. A person with weak muscles may use them close to their maximum only for a short period of time, e.g., climbing stairs. Thus, there will be no time for adaptation to endurance. By reducing the intensity, such as walking slower and taking short breaks for other types of activity, both resistance and endurance training at an appropriate level may be achieved. Another way is to choose a medium where the load can be more individualized between muscle groups as in pool training. In a study with a control group at our polio clinic, increased general endurance and less pain in daily life was demonstrated in the group with pool training compared to the group that received advice about their physical

activity. There was no deterioration of function after the pool training (Willén et al, 1999).

Other training studies indicate the possibility of improving the general endurance of polio persons by using individual training programs, as on a bicycle ergometer, or group training on the floor with combined endurance and submaximal resistance training with music (Ernstoff et al, 1996). In general, it would be of value to encourage endurance types of programs with proper intensity and the possibility of individualizing the load as in pool training, giving proper time for rest between the exercises.

The role of resistance training for polio muscles is more controversial. However, short-term resistance training at high or maximal intensity has been demonstrated to give an increase of muscle strength in moderately affected muscles, measuring more than 3 on the manual muscle testing scale (Einarsson, 1991). Such an increase in strength seems to be maintained, probably by adaptation of the physical activity level in daily life, and could be beneficial and allow a broader type of exercises with relatively less effort. Such a program did not result in any negative effects or evidence of muscle damage when properly supervised. Also low intensity strength training can improve muscle performance and reduce the experience of fatigue. There was no change in serum creatine kinase after a 12-week muscle-strengthening program, which would have indicated muscle damage (Agre et al, 1997).

**TO LEARN THE APPROPRIATE LEVEL OF PHYSICAL ACTIVITY TO AVOID UNNECESSARY OVERLOAD ON THE ONE HAND AND DISUSE ON THE OTHER IS IMPORTANT FOR MAINTAINING OPTIMAL PHYSICAL FUNCTION IN POLIO-AFFECTED MUSCLES.** As important is to avoid pain, it being both a limiting factor for physical performance and an indication of overload that could be on muscles as well as joints and other tissue structures. The experi-

ence of pain is evidently closely related to physical activity. Individuals who spontaneously chose a walking speed close to their maximum speed were more prone to experience pain in their daily life (Willén et al, 1998). The results of that study indicated also that those who were less affected by muscle weakness experienced more pain than individuals with weaker muscles, and they might, thus, have a pattern of daily activity that was too strenuous. Advice and adaptation of the daily physical activity to avoid pain is an important feature in the post-polio management. ■

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EIGHTH INTERNATIONAL

# Post-Polio AND Independent Living Conference

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**June 8-10, 2000**

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Educating health professionals is another goal of this conference. **Learning About and From Post-Poliomyelitis: A Seminar for Physical and Occupational Therapists and Physical and Occupational Therapist Assistants** is scheduled for Friday, June 9 (7:45 am – 4:45 pm) and Saturday morning, June 10 (7:45 am – 11:45 am). Attendees will be awarded a certificate of attendance for 9½ contact hours.

### *Sessions include:*

- ◆ Pathophysiology of Acute Poliomyelitis and Post-Polio Syndrome
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- ◆ Complementary/Alternative Therapies: How to Decide
- ◆ Practicing New Skills

Because the entire conference offers sessions for health professionals, we encourage PT/OT seminar attendees to register for all three days.

PRELIMINARY PROGRAM AND REGISTRATION details are in the Winter issue of the *Rehabilitation Gazette* (Volume 40, Number 1) mailed to all *Polio Network News* subscribers.

**READERS: HELP US NETWORK! LET OTHERS KNOW ABOUT THIS VALUABLE LEARNING EXPERIENCE.** Contact Carol A. Cox at GINI (see contact information at the top of this page) to:

- ◆ Obtain additional copies of *Rehabilitation Gazette* (Volume 40, Number 1) to distribute.
- ◆ Submit names of health professionals, polio survivors, ventilator users, and service providers for GINI to send registration information.
- ◆ Volunteer services-in-kind or your assistance.



# Osteoporosis Research: Assessment of Bone Density and Limb Function

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## THE RESEARCH

We all know that our polio-affected limbs are shorter and thinner than our unaffected ones. Most of us have seen x-rays showing that the affected bones are much thinner than the "normal" ones. Are they only smaller and thinner, but of typical strength? Or, are they actually weaker in structure, osteoporotic?

## PRELIMINARY STUDY RESULTS

We studied 38 individuals who had residual weakness in one or more limbs after acute poliomyelitis. Polio onset was at a mean age of 53 years, (median 49, range 42-75). There were 11 men, mean age 61.3 years (60, 43-75) whose mean age of polio onset was 5.5 years, (1, 0-26). The 27 women had a mean age 62.9 years (range 41-85 years) at the time of the study. Four were premenopausal, 2 perimenopausal. The mean years since menopause of the 18 postmenopausal women was 17.7 years, (19, 1-34), mean age of polio onset of all women 10.7 years, (6, 1-37).

Six subjects developed polio after age 17, when they were fully grown. One man, now age 73, had polio at age 17. The mean age of the five women is now 70.7 (72, 62-73) years, onset mean age 30.4 (31, 24-37).

Weakness in individual limbs was self-assessed in a structured clinical interview on a 4-point grading system for the extensors and flexors of the upper and lower segments of

each limb for the current function, previous function during stable years, and at onset, where practicable.

Bone mineral content (BMC), lean tissue (LN), and bone area (BA) were measured in duplicate (with repositioning) in whole body scans for each subject using a fan beam Hologic QDR 4500 densitometer with regions of interest defined for whole limbs and parts of limbs.

Unilateral involvement occurred in 40 limbs (arms 18, legs 22), and bilateral in 16 limbs (arms 5, legs 11). *In all, there was a history of 47 fractures that occurred in 25 of the 38 cases.* Thirteen fractures were in long bones, of which 2 were at the lower end of the shaft of the femur (each in a polio-affected limb), 2 were at the femoral neck, with 5 tibial, 4 forearm, and 1 humeral.

For individual limbs BMC vs LN (dependent variable) the correlation coefficient (and regression estimate) was:

right arm (RA)	0.88	(15.4)
left arm (LA)	0.90	(16.8)
right leg (RL)	0.87	(18.2)
left leg (LL)	0.82	(18.1)

Thus for every unit (gm/cm<sup>2</sup>) increase of BMC in a limb, the estimate of lean tissue rose by 15-18 gms.

Associations of bone area vs. lean tissue:

right arm (RA)	0.80	(16.7)
left arm (LA)	0.82	(18.0)
right leg (RL)	0.84	(28.1)
left leg (LL)	0.70	(26.0)

The legs show a greater increase in lean tissue than the arms for any unit increase in projected bone area across the study population, with the results for all limbs pooled.

When comparing the arithmetic percentage difference in BMC and LN between abnormal and normal limbs for arms and legs separately, arms 0.75 (0.65), legs 0.85 (0.95), i.e., for every unit change in percentage difference in BMC between limbs there is a 0.65 gm percentage difference in LN in the arm and a 0.95 gm percentage difference in the leg. All correlations quoted were at the p=0.0001 level of significance.

## CONCLUSIONS

Our data show that there is a strong association between the bone content (BMC) and lean tissue or muscle bulk (LN) in normal and atrophic limbs in post-polio individuals and that polio-affected limbs have a lower bone mineral content, in proportion to the reduction in muscle bulk. There also is an apparent association in the size of the limb (bone area, BA) and muscle bulk (LN), particularly in people whose polio developed at an early age. We had insufficient numbers of cases that developed polio after the age of 17 to allow us to analyze these effects independent of growth.

At this stage, we cannot say which of the two factors (muscle bulk or size of the limb) has the more important influence on bone content, but we suspect it is the muscle bulk. These results require further statistical analysis, particularly multivariate analysis of the factors that might predict BMC.

We suspect that the numbers of fractures, particularly the fractures of the femur, are more than would be expected in people of this age.

Adapted from *Assessment of Bone Density and Limb Functions in Subjects Who Have Had Acute Poliomyelitis in the Past* presented to the New Zealand Society of Endocrinology, Palmerston North (November, 1998) and to the Professor David Stewart Symposium, Dunedin (February, 1999). Other researchers involved in this project, in addition to polio survivor M. Elizabeth Falkner, include John W. Delahunt, Department of Medicine, Wellington School of Medicine; Robyn Green, Department of Public Health, Wellington School of Medicine; Jeremy Krebs, Capital Coast Health, Wellington Hospital; and Harry McNaughton, Department of Medicine, Wellington School of Medicine.



This study was not designed to assess fracture incidence and we cannot conclude this without a formal study (one is being planned).

If muscle bulk is subsequently shown to be more significant than limb development in the determination of limb BMC, a program of physical therapy seems unlikely to develop muscle bulk to the extent to reverse the loss of bone density, although it may minimize the amount of loss with age. Direct therapies to increase bone density, such as those being developed (for example, weight bearing during low-intensity vibrating stress), are likely to be more relevant. In fact, these may be more effective than the standard drug treatments for osteoporosis. The choice between a general drug treatment and a local limb physical treatment may (at least in part) depend on the general risk of osteoporosis, as assessed by standard DEXA scans of the hip and wrist in non-involved limbs.

#### WHAT DID OUR RESEARCH SHOW?

Yes, polio-affected limbs ARE weaker in actual structure; they are indeed relatively osteoporotic — even if the rest of our bones are not.

What about the progression of weakness? This is where the second stage of the research comes in — we have enough funds to repeat all the scans a year after the initial investigations. Several things will be interesting about this second step. We will repeat all the questionnaires on the degree of disability caused by polio both to show how reproducible people's accounts are to map deterioration over the year, to demonstrate any deterioration in bone density over the year, and to note any new fractures.

The study was largely funded by the Otago Medical School. The Post-Polio Support Society New Zealand, Inc. donated \$1,000 to support this research.

This article was first published in *Polio News*, the newsletter of the Post-Polio Support Society New Zealand, Inc., edited by Denis Hogan.

#### WHAT OF POSSIBLE TREATMENT?

Everyone, men and women, would be well advised to have ordinary bone mineral density tests done. Men and pre-menopausal women can be affected, particularly if they get little weight-bearing exercise.

Anyone with generalized osteoporosis should definitely seek treatment, including a choice of many different drugs (not only hormone replacement) as well as lifestyle optimization.

What we do not know is whether ordinary medical bone-strengthening treatment will help people who have osteoporosis only in their polio-affected limbs. We speculate it will have only a limited effect. As there may be a relationship between the muscle or use of the limb and the bone content, it may be more beneficial to use local treatments. Weight-bearing on a vibrating surface is a physical technique being developed and that may be of interest to polio survivors.

If you have an ordinary bone density test (of lumbar spine and femoral neck) that is reported normal, it might be worth having a total body scan. Your physician can write a request to the radiologist to comment on osteoporosis in the individual limbs. However, this can be costly. After receiving the results, discuss with your doctor or an endocrinologist whether you should try a bone-strengthening drug for two years.

Also, then you can decide whether you want to take something that will help the osteoporosis in your polio limb. However, we do not know whether it would make any difference or not.

If you do decide to go down this path, we would be very pleased if you would send us copies of your bone density results and your treatment plan.

Please send the information to M. Elizabeth Falkner, MB, BS(Lond), LRCP(Lond), 132 Cole Street, Masterton, New Zealand. ■

## INTERNATIONAL POLIO NETWORK

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# More About Osteoporosis

**Osteoporosis** is a debilitating disease in which bones become fragile and are more likely to break. In most cases, it can be prevented and treated but if steps are not taken, it progresses painlessly until a bone breaks.

Osteoporosis affects more than 28 million Americans, 80% of whom are women. In the United States today, 10 million already have osteoporosis and 18 million more have low bone mass placing them at increased risk for developing it.

People need to know whether they are at risk for developing osteoporosis or whether they already have lost so much bone that they already have osteoporosis. While risk factors (see box below) can alert a person to the possibility of low bone density, only a bone mineral density (BMD) test can measure current bone density, diagnose osteoporosis, and determine fracture risk. There are many different techniques that measure BMD painlessly and safely. The majority of these machines use extremely low levels of radiation while ultrasound machines use sound waves instead.

Medicare and many private insurance carriers cover bone density tests to detect osteoporosis for individuals who meet certain criteria. Talk with your doctor about whether or not this test would be appropriate for you.

Depending on the results of the test, you and your physician may decide that you should begin a Food and Drug Administration (FDA) approved medication for osteoporosis to stop bone loss, improve bone density, and reduce fracture risk.

**Several medications** have been developed to help manage osteoporosis and to strengthen bones in women at high risk for the disease. Hormone replacement therapy (HRT – estrogen and progesterone) helps to prevent osteoporosis by slowing bone loss. However, HRT carries certain risks, most notably an increased risk of breast cancer, and may not be the best choice for some women.

Other medications are available to prevent and manage osteoporosis without the risks associated with HRT. *Alendronate*, a drug known

## Tips for Taking Supplements

– Avoid the use of bone meal or dolomite (these may contain lead or other toxic metals) unless the supplement has the USP symbol, a sign of purity.

– Calcium is best absorbed when taken in small amounts (500 mg or less) throughout the day.

– More is not necessarily better. Too much calcium can flood your body's absorption sites and keep you from getting enough iron, magnesium, and zinc.

– Drink plenty of fluids.

– Consult your physician about possible interactions between calcium supplements and other prescription or over-the-counter medications. Ask your pharmacist to recommend a supplement.

as a bisphosphonate, slows bone loss and increases bone density. Another medicine, *calcitonin*, has been shown to improve bone density and lessen back pain due to osteoporosis. *Raloxifene*, developed to help prevent osteoporosis, belongs to a class of drugs called SERMs, or "selective estrogen receptor modulators." Raloxifene has been shown to build bone without increasing the risks of breast or uterine cancer.

**You can do your part** to protect bone health by following osteoporosis prevention and treatment strategies.

- Consume a calcium rich diet that provides 1200 mg of calcium from a combination of foods and supplements.
- Obtain between 400 and 800 IU of vitamin D each day.
- Participate in weight-bearing and resistance-training exercises three times a week. This recommendation by the National Osteoporosis Foundation needs to be modified for polio survivors. Each polio survivor must determine what is a beneficial level of exercise and what could be deleterious. (See front page article.)

## Factors that increase your chances of developing osteoporosis:

**Gender** – Women are more likely to develop osteoporosis than men due to thinner, lighter bones and the decrease in estrogen production that occurs during menopause.

**Age** – The longer you live, the greater the likelihood of developing osteoporosis. Although all of us lose bone tissue as we age, the amount and rate of loss varies widely with each individual.

**Family History** – Susceptibility to osteoporosis is due in part to heredity. If you have had a fracture as an adult or a parent has had a fracture, you are more likely to have low bone mass than your peers.

**Ethnicity** – Caucasian and Asian women are at highest risk; African-American and Hispanic women are at lower but significant risk.

**Body Size** – Low body weight (under 127 lbs) and a small-boned frame place you at increased risk.

**Lifestyle** – A diet low in calcium, inadequate vitamin D, little or no exercise, current cigarette smoking, or excessive use of alcohol are all risk factors for this debilitating disease.



## Prevention of Falls and Fractures

### Safety First to Prevent Falls

At any age, people can improve their environments in ways that reduce their risk of falling and breaking a bone.

### Outdoor Safety Tips

- ❑ In nasty weather, use a walker or cane for added stability.
- ❑ Wear warm boots with rubber soles for added traction.
- ❑ Look carefully at floor surfaces in public buildings. Many floors are made of highly polished marble or tile that can be very slippery. When floors have plastic or carpet runners in place, stay on them whenever possible.
- ❑ Identify community services that can provide assistance, such as 24-hour pharmacies that deliver, grocery stores that take orders over the phone and deliver, especially in poor weather.
- ❑ Use a shoulder bag, fanny pack, or backpack to leave hands free.
- ❑ Stop at curbs and check height before stepping up or down. Be cautious at curbs that have been cut away to allow access for bikes or wheelchairs. The incline up or down may lead to a fall.

### Indoor Safety Tips

- ❑ Keep all rooms free from clutter, especially the floors.
- ❑ Keep floor surfaces smooth but not slippery. When entering rooms, be aware of differences in floor levels and thresholds.
- ❑ Wear supportive, low-heeled shoes even at home. Avoid walking around in socks, stockings, or floppy, backless slippers.
- ❑ Check that all carpets and area rugs have skid-proof backing or are tacked to the floor, including carpeting on stairs.
- ❑ Keep electrical cords and telephone lines out of walkways.
- ❑ Be sure that all stairwells are well lit and that stairs have handrails on both sides. Consider placing fluorescent tape on edges of top and bottom steps.
- ❑ For optimal safety, install grab bars on bathroom walls beside tubs, showers, and toilets. If you are unstable on your feet, consider using a plastic chair with a back and non-skid leg tips in the shower.
- ❑ Use a rubber bath mat in the shower or tub.
- ❑ Keep a flashlight with fresh batteries beside your bed.
- ❑ Add ceiling fixtures to rooms lit by lamps only or install lamps that can be turned on by a switch near the entry point into the room. Another option is to install voice- or sound-activated lamps.
- ❑ Use at least 100-watt bulbs in your home.
- ❑ If you must use a step stool for hard to reach areas, use a sturdy one with a handrail and wide steps. A better option is to reorganize work and storage areas to minimize the need for stooping or excessive reaching.
- ❑ Consider purchasing a portable phone that you can take with you from room to room. It provides security because not only can you answer the phone without rushing for it, but you can also call for help should an accident occur.
- ❑ Do not let prescriptions run low. Always keep at least one week's worth of medications on hand at home. Check prescriptions with your physician and pharmacist to see if they may be increasing your risk of falling. If you take multiple medications, check with your physician and pharmacist about possible interactions between the different medications.
- ❑ Arrange with a family member or friend for daily contact. Always have at least one person who knows where you are.
- ❑ If you live alone, you may wish to contract with a monitoring com-

pany that will respond to your call 24 hours a day.

- ❑ Watch yourself in a mirror. Does your body lean or sway back and forth or side-to-side? People with decreased ability to balance often have a high degree of body sway and are more likely to fall. ■

SOURCE: National Osteoporosis Foundation, 1232 22nd Street NW, Washington, DC 20037 (202-223-2226, [www.nof.org](http://www.nof.org)).

## Memory and Aging

Not all changes in memory are due to disease, but some that accompany normal aging may be amenable to forms of treatment that are also under study as possible Alzheimer therapies. One involves the hormone estrogen, thought to protect against a variety of conditions including osteoporosis and cardiovascular disease, but doctors are cautious about its use because it may increase the risk of breast cancer.

In recent years, studies have suggested that estrogen protects memory. In 1998, an observational study of more than 700 healthy postmenopausal women, led by researchers from Columbia University College of Physicians and Surgeons, found that those who used estrogen replacement therapy scored significantly higher than non-users on memory tests, and also on tests of language and abstract reasoning. Moreover, the estrogen-users' performance on a test of verbal memory improved slightly during an average 30 months of follow-up, as they continued on estrogen replacement therapy. These preliminary results suggest the time may be ripe for clinical trials of estrogen as a memory strengthener during healthy aging (Jacobs et al, 1998). ■

SOURCE: The Dana Alliance for Brain Initiatives' "Delivering Results: A Progress Report on Brain Research, Update 1999: New Connections."



## POST-POLIO BIBLIOGRAPHY

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In search of an appropriate instrument with which to detect a decline in strength in PPS, an investigation was made of the validity, the reproducibility, and the ability of the Citec HHD to detect intraindividual changes in former polio subjects. The device has good validity in the lower force range. However, because the agreement between measurements was poor, it has limited ability to detect a change in muscle strength. Therefore, this method is unable to detect small changes in lower extremity muscle strength in former polio patients.

*Post-polio related poster sessions at the American Academy of Physical Medicine and Rehabilitation (AAPM&R) 61st Annual Assembly and Technical Exhibition in conjunction with 13th World Congress of the International Federation of Physical Medicine and Rehabilitation, Washington, DC, November 1999:*

Silver, J.K., Aiello, D.D., & Drillio, R.C. (1999). Light weight carbon fiber and Kevlar floor reaction AFO in two polio survivors with new weakness. [Abstract]. *Archives of Physical Medicine & Rehabilitation*, 80(9), 1180.

The primary goal of bracing in polio survivors is to provide adequate support for functional mobility while using the lightest weight brace possible in order to not overly fatigue a limb that is already weak. We present 2 cases of polio survivors without a prior history of bracing who developed new weakness, muscular fatigue, and pain in their legs as well as problems with gait and balance. Both patients tried a prefabricated narrow leaf polypropylene ankle foot orthosis (AFO) that they found to be cumbersome, heavy, and difficult to use. They then tried a prefabricated floor reaction AFO made of a combination of carbon fiber and Kevlar that was approximately 40% lighter than its polypropylene counterpart. Both patients found this brace much lighter and easier to use. In both cases, the patients have used the brace daily

with almost complete resolution of their lower extremity pain and marked improvement in balance and gait. Although these materials are more expensive and difficult to modify than polypropylene, in some instances, due to their light weight and flexibility, they provide superior comfort and gait performance as well as help to conserve energy in weak and easily fatigued muscles. Contact Julie Silver, MD (silver.julie@mgh.harvard.edu).

Reid-Artist, J.M., & Martin, J.R. (1999). Threshold electric stimulation to improve functional outcome in post-polio patients. [Abstract]. *Archives of Physical Medicine & Rehabilitation*, 80(9), 1141.

Threshold electrical stimulation (TES) stimulates the growth of atrophic muscle by transmitting low-level electrical impulses through the skin to underlying tissues. At Bacharach Institute for Rehabilitation it is used in patients with postpolio syndrome in conjunction with an exercise program. The treatment is given at night when the patient is asleep. The patients selected are those who have disuse muscle atrophy and have been on an exercise program and show a plateau or decline in their functional abilities. We have documented evidence of functional gains in 9 out of 11 patients. Two were lost to follow-up. With TES, the patients showed further functional gains, most of them at 3-month follow-up evaluation. Video documentation has shown improved ability to transfer, increased foot clearance through the swing phase of gait, improved bed mobility, increased time for unilateral stance, and increased active isolated motion against gravity, and other motor functional gains. We conclude that TES can be used as a valuable adjunct to an exercise program for selected postpolio patients. Contact Jack Martin, PT (oppt@bacharach.org). ■

**Post-Polio Directory 2000** will be available March 1st. Entries from 1999 are being confirmed. Listings include self-identified clinics and health professionals knowledgeable about the late effects of polio and support groups. The cost is \$5 USA, \$6 Canada, Mexico, and overseas surface; and \$7 overseas air. (US dollars only)

## POST-POLIO SYNDROME SLIDE KIT

A slide kit (English only) appropriate for a comprehensive lecture on post-polio syndrome to health professionals was produced by the Post-Polio Task Force and funded by ICN Pharmaceuticals, the manufacturers of Mestinon (pyridostigmine). The kit, containing 54 slides and a script, covers the epidemiology, natural history, definition, diagnosis, pathophysiology, evaluation, and management of post-polio syndrome.

A limited number of free copies of the Post-Polio Syndrome Slide Kit is available from International Polio Network (IPN). Readers who would like to assist IPN in distributing this informational resource to the training programs of health professionals (medical schools, physical therapy and occupational therapy programs, etc.) are asked to send a letter to International Polio Network, 4207 Lindell Boulevard, #110, Saint Louis, MO (Missouri) 63108-2915 USA. Please include the name, title, and address of the individual to receive the kit, along with a brief explanation as to how the kit will be used. ■

The Revised Edition of the **Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors**, ISBN 0-931301-04-1 pbk. (1999), a 120-page book in dictionary format containing 90 entries, is a compilation of the research and experience of more than 40 experts. Cost is \$15 each (US dollars only), plus \$3.50 total shipping and handling for 1-5 copies shipped within the USA, or plus \$4.50 for 1-5 copies shipped outside the USA. Send check made payable to GINI or credit card information to International Polio Network. ■



## Readers Write

"The new issue of *Polio Network News* arrived today. Depression is an important topic and deserves the special treatment you have given it.

"My recent analysis, which I am currently writing up, of the second RRTC Study on Aging with Disability is not consistent with the statistic cited at the beginning of the issue. Ironically, that statistic comes from a summary of the article I was third author on with Bryan Kemp, PhD. That summary was based on the first five-year study, using a smaller sample and a different measure of depression, whereas my recent findings are from the second and larger study.

"One way to clarify this seeming discrepancy is to indicate that while the average depression score for the entire polio sample was within the normal range (5.5) and not significantly different from non-disabled controls (4.2), within the polio sample significant differences were observed. Polio survivors meeting the criteria for post-polio syndrome had significantly higher depression scores (mean = 6.5) than both their polio counterparts without post-polio syndrome and controls."

—Margaret L. Campbell, PhD  
Vienna, Virginia

"We had tried all the usual things to spread the word about the late effects of polio. Then, last year, we decided to try something new. Why not rent a booth at the Iowa State Fair? And, we did!

"We rented space where other health care groups display, made a large banner, dug through the old newspaper microfilms at the library, and enlarged some articles and made posters. We had bookmarks printed with symptoms and addresses for obtaining additional information and we printed a special Iowa State Fair edition of our newsletter. We displayed a map of Iowa and asked visitors who had polio to mark their home town. Our members volunteered to man the booth



At the Iowa State Fair

in four-hour shifts for the entire 10 days. Our group spent about \$1,000 including rent, insurance, and printing. Then ... we settled down to wait!

"What we learned was interesting and enlightening. We heard familiar, different, and sad stories. We heard our stories and we learned that:

- A large number of those passing our booth had either polio themselves or someone in their immediate or extended family had polio and almost all knew someone who had the disease.

- Many young children had never heard of polio.

- Some people did not want to admit that they had ever had polio or did not want to talk about it.

- Others admitted that they had polio, but were very quick to state that they 'were over it' now and had no problems.

- Others who had never heard of the late effects of polio did comment about the leg (or foot or arm or shoulder) that bothers them. 'I just figured it was old age.'

- Children accompanying their parents did not know that their parent had polio. Spouses appeared more interested in the material than the survivor.

- Some were so grateful to receive the information and requested

much, much more. Some were relieved to be able to discuss what was happening to them.

- Some appeared to be uncomfortable seeing many of us using wheelchairs, scooters, and canes, and wearing braces.

- One individual told of his brother having polio and remembering that he himself could not walk and laid on the couch with his mother rubbing his legs with bacon grease. After about a week, he got up and walked. He stated he 'had not had polio.'

- A few reminisced with us about their long stay in the hospital. We did not hear stories of mental and physical abuse. We spoke with many polio survivors who were not hospitalized and who were cared for at home with patent and home remedies."

—Pat Moreland, RD, LD, MPA  
Iowa Polio Survivors Group

"I was a polio patient at the New York State Reconstruction Home (now the Helen Hayes Hospital) in West Haverstraw, New York from 1944 to 1947. I would like to contact any polio survivors from that place and time."

—Jack Perkins  
(jhp1185@webtv.net  
or contact International  
Polio Network)

CONTINUED ON PAGE 10



"Recently at a neuropathy meeting, I had a discussion with a fellow member who suggested that I write to *Rehabilitation Gazette* to let people know about a neck brace I designed.

"After breaking my neck in 1966, (which went undiagnosed for three years), my condition deteriorated to the point where I was dragging one leg behind me when I walked and I had limited use of my right arm. I had a spinal fusion, but in 1982 I suffered a severe whiplash injury. Not being a candidate for further surgical procedures, I wore various types of collars. None of these relieved my pain or aided in my recovery. I then decided to design my own brace. My original brace was made of stainless steel, which



had numerous drawbacks, including but not limited to its weight. I have made many improvements. In its current configuration, the brace is adjustable in four different ways. The adjustments allow it to align the spine, support the weight of the head (off the neck), and secure the head in a position to ease pain.

"Further research has created a brace that accommodates people who have a trachea tube (see photo). With this new non-invasive brace, the tubing can be changed without removing the brace and vice versa."

—Charles McGuinness,  
McGuinness Orthopaedic  
Brace Corporation, 10 Karen  
Avenue, Plainview, NY 10803

## POTPOURRI

◆ An Award Winner – **A Paralyzing Fear: The Story of Polio in America** was nominated for three Emmys – Best Music, Best Research, and Best Editing. The film, written and directed by Nina Gilden Seavey, won the Emmy in the Best Research category. Additional honors include the Erik Barnouw Prize for the Best Historical Film of the Year, the Golden Hugo for the best film in History and Biography, the Golden Apple for Outstanding Achievement in Educational Filmmaking, and the Axiem Award for the Best National Documentary.

The program was supported by the National Endowment for the Humanities, The George Washington University, Corporation for Public Broadcasting, Wyeth-Ayerst Laboratories, Wyeth-Lederle Vaccines, and the March of Dimes Birth Defects Foundation.

The film has also been sold in Australia to Australian Broadcasting Corporation and aired at the end of October 1999. It is also in home video distribution in Australia and New Zealand.

*NOTE: Contrary to what has been circulated on the Internet, no one has an agreement to work with Nina Seavey on a follow-up video. Polio survivors are advised to be cautious of individuals asking personal questions and should obtain complete contact information from the individual before answering any questions.*

◆ GINI has been asked by the University of Texas at Austin School of Nursing to assist them in **a study funded by the National Institutes of Health regarding health promotion and quality of life.** Many of you will receive a letter of introduction and will have an opportunity to participate, or not. The choice is yours. Be assured that GINI does not give or sell your name and information to anyone.

◆ **The Ticket to Work and Work Incentives Improvement Act of 1999** was signed by President Bill Clinton December 17, 1999. Highlights of the new legislation include two new options for states to offer the Medicaid buy-in for workers with disabilities and provides \$150 million in grants to encourage states to take this option; creates a new \$250 million Medicaid buy-in demonstration to help people whose disability is not yet so severe that they cannot work; extends Medicare coverage for an additional four-and-a-half years for people in the disability insurance system who return to work; and enhances employment-related services for individuals with disabilities through the new "Ticket to Work" program.

◆ A Web site from Medicare features important up-to-date information about health plan options. Go to **www.medicare.gov** to find:

– Information on Medicare eligibility and enrollment and instructions on how to read a Medicare summary notice.

– Detailed information about Medicare health plan options. You can click on the Medicare Compare database to obtain side-by-side comparison information on the cost and benefits for Medicare health plans in your area. You can also get quality and satisfaction ratings for managed care plans.

You can also access the Nursing Home Compare database to get side-by-side comparison information on every Medicare and Medicaid-certified nursing home nationwide, including the most recent inspection results.

◆ Created last year by the federal government, a new benefit, **QI-1 (Qualified Individuals-1)**, pays the \$45.50 monthly Medicare Part B (supplemental medical insurance) premium for beneficiaries with monthly incomes of less than \$947 and savings of less than \$4,000.



For couples, the eligibility threshold is \$1,265 in monthly income and \$6,000 in savings. Contact your closest Social Security office for more details.

◆ **Medicare** has lifted the \$1,500 financial limitation on all outpatient physical therapy, occupational therapy, and speech-language pathology services. Although claims for therapy services will not be subject to a financial limitation, claims may still be reviewed to ensure that the services rendered are covered (including being reasonable and necessary).

◆ **A donation** of \$50 million from Bill Gates, chairman of Microsoft Corporation, and \$28 million from the United Nations Foundation, established by Ted Turner, founder of Cable News Network, now a unit of Time Warner Inc., will go toward polio vaccines and disease surveillance in some of the world's poorest countries.

◆ The Interior Department, in connection with last year's announcement that there would be an addition to the **FDR Memorial** depicting Franklin Delano Roosevelt in his wheelchair, requested \$3.5 million to construct a "fifth room" for the new statue. Congress originally provided no funding, and then offered \$2 million. But, in the final negotiations, activists were able to secure \$3 million for the FDR Memorial addition.

◆ **The North American Spine Society** is collecting archival memories, documents, and artifacts for the purpose of documenting its history and creating a museum dedicated to the practice of spine care. They are looking for donations of any items related to either the history of NASS or spine care including photos and/or videos of spine care procedures and techniques; instruments/implants/products/artifacts integral to the practice of spine care in the past or present; old promotional materials for spine

care products; classic research studies; and oral histories/biographical items related to individuals of importance to the field. All donated items should be accompanied by a brief description and will be catalogued in such a way to recognize contributors when displayed. Contact Pam Hayden, Manager of Scientific Affairs, North American Spine Society, 8320 St. Moritz Drive, Spring Grove, IL (Illinois) 60081 (815-675-0021, 815-675-3137 fax, HaydenP@aol.com).

◆ A new free brochure from Combined Health Information Database (CHID), **Incontinence ... You Are Not Alone: A Step-by-Step Guide to Treating Incontinence**, discusses three steps in dealing with urinary incontinence: understanding, taking action, and treating incontinence. Contact the American Urological Association Inc., 1120 North Charles Street, Baltimore, MD (Maryland) 21201 (877-DRY-LIFE, www.drylife.org).

◆ **Rainbow Wheels** offers daily, weekly, monthly, and long-term rental of accessible vans. The mini and full-size vans feature lowered floors, raised roofs, 4-point wheelchair tie-downs, front/rear heating and air conditioning, power locks and windows, privacy tinted windows, removable passenger seat allowing up-front riding, and hand controls/transfer seat bases for independent driving.

For more information, contact Rainbow Wheels, P.O. Box 194, Hillsdale, MI (Michigan) 49242 (800-910-VANS, 517-439-1089 fax, rainbow@dmci.net, www.rainbowwheels.com).

◆ **TIME** is now producing a weekly large print edition. **TIME Large Edition** features 16-point type and maintains the editorial content of the regular edition with a minimum of 80% of the regular content.

Call 800-552-3773 to subscribe (54-week introductory offer is \$79.97).

#### ◆ The **Haseltine Systems**

Corporation manufactures the Haseltine Flyer™, a durable polyethylene case for protecting wheelchairs and scooters during airline flights. They offer three variations of the case, in three colors, with an internal strapping system and padding system. Contact Haseltine Systems Corporation, 340 McKinley Avenue, New Haven, CT (Connecticut) 06515 (888-445-8751, 203-397-3043, www.haseltine.com). ■

## Trouble Flying?

International Polio Network has received several questions lately from seasoned flyers who are now experiencing more problems when flying. We request that you send us your recent experiences – positive and negative. We would like to know how you fly with needed equipment you cannot lift, how you work with airline personnel in transferring yourself from wheelchair to seat, if you have any special device that supports your body while being transferred, etc., etc.

The following chart is a correction for page 3 of *Polio Network News*, Fall 1999, Vol. 15, No. 4:

**From 1937-1950, the USA total cases included both paralytic and nonparalytic polio.**

Year	Reported Cases
1937	9,514
1938	1,705
1939	7,343
1940	9,804
1941	9,086
1942	4,167
1943	12,450
1944	19,029
1945	13,624
1946	25,698
1947	10,827
1948	27,726
1949	42,033
1950	33,300
Total	226,306



## Proposals Due March 1

The GINI Research Fund is seeking proposals for its first \$20,000 grant. The deadline for phase one of the review process is March 1, 2000.

For more details, contact Joan L. Headley at 314-534-0475 or [gini\\_intl@msn.com](mailto:gini_intl@msn.com). ■

## Symposium in Warm Springs

The March of Dimes Birth Defects Foundation, in collaboration with the Roosevelt Warm Springs Institute for Rehabilitation, will sponsor an international symposium on post-polio syndrome in Warm Springs, Georgia in May 2000.

Attendance is by invitation only. The two-day symposium of experts will review current information on the causes of the syndrome and will promote information exchange on best practices regarding diagnosis, treatment, and management of post-polio syndrome.

Given its historical role in the development of the polio vaccines, the March of Dimes has offered its support and will provide guidance to the process of developing consensus and disseminating the results of the conference in the United States and worldwide.

For more information, contact Joan Roe (914-997-4777, [jroe@modimes.org](mailto:jroe@modimes.org)). ■

## GINI Founder Remembered in Missouri History Museum

Gini Laurie, founder of Gazette International Networking Institute (GINI), has been remembered with a permanent exhibit in the new Emerson Electric Center of the Missouri History Museum. Gini, a native of Saint Louis, is honored for her life-long work on behalf of people with disabilities in a section that asks the question, "What does it mean to be a citizen?" The colorful display on disability rights is located in the McDonnell Douglas Gallery "Seeking St. Louis - Reflections," on the upper level. A large plaque features the following tribute to Gini:

### INDEPENDENT LIVING: GINI LAURIE

Saint Louis' Gini Laurie worked to end institutionalization of people with disabilities. Born Virginia Grace Wilson in 1913, Gini was named after 2 older sisters who died of polio. As a hospital volunteer, she founded *Rehabilitation Gazette*, which became an internationally known advocacy journal. Known as the "grandmother" of the independent living movement, Laurie urged people with all kinds of disabilities to work together to end institutionalization and to support independence. In 1974, she helped found the American Coalition of Citizens with Disabilities. She died in 1989, not long before the Americans with Disabilities Act at last realized her goal of equal rights for people with disabilities.

Also featured are her volunteer badges, copies of *Rehabilitation Gazette*, and the photograph of her holding the prestigious St. Louis Award that she received in 1986.

The Missouri History Museum (Jefferson Memorial Building and Emerson Electric Center), located at the junction of Lindell and DeBaliviere Boulevards in Forest Park in Saint Louis, Missouri, is open daily from 10 am to 6 pm and Tuesday from 10 am to 8 pm. The museum, which is free, is closed Thanksgiving, Christmas, and New Year's Day. For more information call 314-746-4599 or log on to [www.mohistory.org](http://www.mohistory.org). ■



**Gazette  
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