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Sixth International Post-Polio and Independent Living Conference

LIVING WITH DISABILITY

Recognizing the Effects of Non-Polio Health Problems on Post-Polio Symptoms

I want to talk about problems unrelated to a polio history and polio residuals: the co-morbidities, or other medical conditions that have nothing to do with one's polio condition but that may occur during the course of living and growing older.

Polio survivors can and do develop common medical problems like diabetes and heart disease, for example, that accelerate the decline in their nerve conduction velocity and further disrupt the functioning of their polio damaged motor units. Such an "extra" medical problem has a bigger effect on the ability of survivors to walk, to care for themselves, or to work than it would in people who have the same degree of diabetes and nerve conduction problems but did not have any original weakness in their muscles from polio nerve damage.

Secondary disability is another name for new medical conditions that can occur during the life of a person with a disability (See *Polio Network News*, Vol. 11, No. 1, p. 3). If we consider previous paralytic polio as the primary disabling condition, and then add in the influences of individual lifestyle and behavior, of the environment, of intrinsic genetic biology, we have the mediating factors that determine whether new pathologies (like coronary artery disease or diabetes or intestinal problems) will progress to result in new impairments (greater weakness) or greater functional limitations (more trouble walking). If you have an initial primary disability (polio), and then you get something else (diabetes), you may develop secondary disabilities of greater impact more quickly than someone without polio. Of course, the degree of impairment and disability can influence one's quality of life.

There are a lot of different trajectories or downhill courses for functional capacity over the lifespan of a

person with polio. I believe that the biggest determinant of the polio survivor's slope is whether they do or do not develop other medical conditions: how many and how severe they are. These conditions lead to the disabling weakness and fatigue associated with the name "post-polio syndrome." Loss of function can occur quickly if you have an injury or a severe, sudden onset of a medical condition. For example, after a heart attack, you have such reduced heart function that you cannot exercise or remain active for very long. This will quickly result in greater muscle weakness and more trouble walking. When such conditions come on, they can rapidly sap your strength and make life much more difficult.

When Lauro Halstead, MD, National Rehabilitation Hospital, Washington, D.C., interviewed some 10 injured post-polio survivors, regarding how long it took them to recover from an injury as compared to people without polio, he estimated that it took approximately 12 times as long. A rule of thumb is that for every one day "normal" people spend in bedrest and undergo deconditioning of muscle, heart, and lung function, they must spend at least two or three days working to regain the lost functional capacity of these organs. Polio survivors may have to spend 10, 12, or 15 days fighting to recover from every one day of forced inactivity.

When my research colleagues and I at the University of Michigan studied co-morbidities, or "other medical conditions," in 120 polio survivors, we found that 35% of them — an amazingly high percentage — had other medical conditions. Furthermore, there was a high correlation between survivors with other conditions and those reporting reduced ability to remain active and do their usual activities, i.e., those who demonstrated functional decline. A common secondary condition associated with functional decline was obesity, and we used 30% over optimal body weight as our definition of obesity, not just a few extra pounds.

Elevated cholesterol ratio was another secondary condition associated with functional decline. I am not sure

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continued on page 2

exactly what this finding means other than that polio survivors are probably more at risk for hardening of the arteries and coronary artery disease, conditions associated with elevated cholesterol levels, because they are less active.

Our study also indicated that polio survivors are at a very high risk for neuromusculoskeletal impairments: more than half had shoulder pain, 58% had abnormalities in conduction velocity of the median nerve at the wrist, and at least 30% had carpal tunnel syndrome. Arthritic changes in the bones of the hand were higher, of course, among people using crutches, or using their hands to move themselves about in a wheelchair.

Another important co-morbidity is depression. Contrary to some previous studies, we did not find an overall increased incidence of depression: only about 18% of the entire sample were depressed, a percentage actually lower than it is for non-disabled groups of people. Living alone and having new health problems were among the strongest correlations with depression. Post-polio people who did not seek out information or professional help, possible indicators of poor coping skills, also were more likely to be depressed.

Overall, I am urging people to not look at post-polio syndrome as a new disease entity in and of itself. Rather, I am suggesting that they consider it from a life-course perspective as an "at risk" condition that results from the original polio and its resultant disability, and that is triggered by the onset of other medical co-morbidities, whether obesity, depression, heart disease, diabetes, stress, or something else. How polio survivors respond, both psychologically and behaviorally, as well as medically, to the onset of this other condition will determine their course of possible functional decline during the rest of their lives.

Consider a person who has been walking with crutches for years and begins to have shoulder pain. There are two ways that one could view this condition. The first is: as the crutch walker gets older and the collagen tissue that supports the structures of the shoulder joint become stiffer and less elastic, the shoulder begins to wear out. This view considers shoulder pain as an age-related, reduced load-bearing ability of the shoulders that causes them to hurt more than they once did. The second viewpoint is: as the shoulders grow less resilient,

they are used less and their muscles become weaker. There may be some shoulder muscle atrophy along with the changes in shoulder joint tissues. At this point, the polio survivor may say, "Oh, my goodness, I am developing post-polio syndrome; my muscles are getting weaker, and, therefore, my shoulders are now hurting because my muscles aren't strong enough to support them any longer. Post-polio syndrome has caused my new pain and inflammation in the shoulder tissues."

These two viewpoints differ in their attribution of causation for shoulder pain. "Attribution theory" suggests that our emotional responses to negative events in our lives is largely determined by our explanation for why the negative event occurred. Did I develop cancer because God is punishing me? ... because I ate the wrong foods? ... because they polluted my water? or ... because cancer sometimes develop by chance? Similarly,

how survivors explain their individual situations can be very important to what they do about their new symptoms.

When I put together Figure 1, *Contrasting Paradigms for Evaluating Post-Polio Syndrome*, for the National Institutes of Health scientists, I wanted to offer that there are advantages in looking at post-polio syndrome as a condition that occurs in the life course of people who have had previous paralytic polio (the holistic model) rather than as a condition that views post-polio syndrome as a new disease and illness (the traditional model).

FIGURE 1
Contrasting Paradigms for Evaluating Post-Polio Syndrome

	Traditional Medical	Life-Course
<i>Viewed as</i>	Disease/Illness	At-Risk Life Event
<i>Goal</i>	Cure	Prevention
<i>Orientation</i>	Treatment	Management
<i>Etiology</i>	Unknown	Known
<i>Promotes</i>	Fear Anger Hopelessness Dependency Multiple Medical Evaluations	Self-Awareness Emotional Growth Information Seeking Life-Style Change Health Promotion

The medical model expects a cure and prescribes treatment, as opposed to the life-course model, which focuses on prevention and management of problems as they occur. On the one hand, we have an unknown cause for a new disease of post-polio syndrome; on the other hand, we have age-related factors and other medical conditions occurring in people with prior polio. I think that the traditional medical model of post-polio syndrome promotes fear, anger, dependency, hopelessness, and feelings that lead to multiple expensive medical evaluations, whereas the broader perspective of "post-polio syndrome" as a life-course event helps promote self-awareness and emotional growth. □

A FINAL NOTE ... Consider the *Stay Well Manual* that can be ordered from the Michigan Polio Network, Inc., 4291 Squire Road, Quincy, MI 49082. It deals with general health issues of nutrition, the proper amount of exercise, and appropriate lifestyle modifications.



Post-polio syndrome demonstrates the difficulty of separating disease from normal aging. When individuals first presented with symptoms of post-polio syndrome, many were told they were just getting older. Some are still given this explanation. To a certain extent this is true, but experience and thoughtful observation reveal a process above and beyond normal aging. There is a slow multisystem decline in aging that interacts with the injury sustained during acute poliomyelitis. In the life of post-polio survivors, a degree of disability emerges that places them on a different trajectory from the slow accumulation of disability experienced in normal aging.

ETIOLOGY OF AGING

The overall cause of aging itself is not known. There are probably several mechanisms operating simultaneously that produce age-related decline in organ and tissue function. In some cells, reproduction is limited to a certain number of generations; distant organ failure may change the systemic milieu in a way that negatively alters cell function. Subtle conformational changes in critical proteins of cell metabolism may damage some cell types. In neurons, the accumulation of byproducts of cellular metabolism during the lifetime of the cell may be injurious.

CHANGES OF NORMAL AGING

In normal aging there is a slow multisystem decline. The onset of decline and rate of change vary from organ to organ.

The heart is fairly resistant to aging. The size of the heart is similar, however the thickness of the heart wall is slightly increased. Early diastolic filling is reduced. There is age-related decrease in maximum heart rate but a compensatory increase in volume per beat. Maximum oxygen consumption is reduced with age but it is uncertain if this is due to decreased cardiac output or decreased peripheral uptake of oxygen.

The forced vital capacity of *the lungs* decreases after age 27 by approximately 25ml/year (1). The surface area of the air sacs in the lungs decreases by 4%

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per decade after age 30 (2,3,4) These changes resemble those in emphysema.

Renal (kidney) blood flow is decreased from 1200ml/min in youth to 600ml/min at age 80.

How well the kidney removes waste products from the blood is stable until the middle of the fourth decade then declines.

Immune system changes also occur with aging (5):

- ◆ the involution of thymus gland;
- ◆ antibody response to vaccination decreases;
- ◆ autoantibodies (antibodies to self structures) increases;
- ◆ T- cell function diminishes;
- ◆ T suppressor cell function increases.

Infectious diseases such as pneumonia and influenza rise exponentially after the age of 25 along with an increased incidence of cancer and autoimmune disease (6,7).

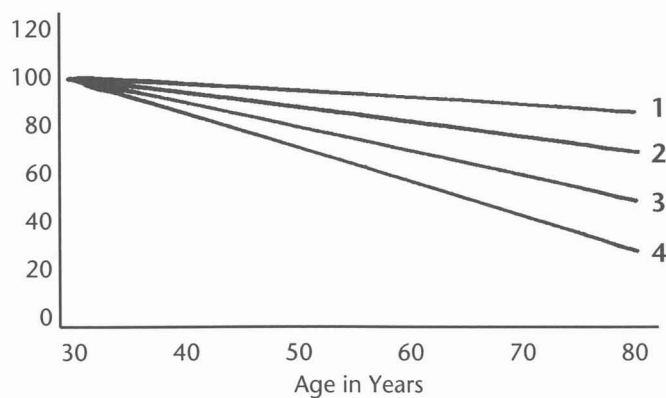
Changes in *the brain* with normal aging include:

- ◆ A decrease in weight;
- ◆ A decrease in cortex nerve cell size;
- ◆ A decrease in the speed of central processing;

continued on page 4

Age Decrements in Physiologic Performance

% of 30-year-old performance



- 1 Nerve Conduction
 - 2 Heart Output
 - 3 Kidney Function
 - 4 Lung Function
- Max Work
Cardiovascular

Shock NW. Discussions on Mortality & Measurement. In Strehler BL, Ebert JD, Shock NW, eds. The Biology of Aging: A Symposium. Am Inst Biol Sci, Wash DC

- ◆ A significant decline in long-term memory (delayed recall) by age 50 (8);
- ◆ A loss of substantia nigra neurons, (400k @ birth, 200k @ age 80). These are the cells of paramount importance in Parkinson's disease. When the count drops to between 200k and 100k, individuals become symptomatic with Parkinson's disease;
- ◆ Aging of an important population of brain motor neurons (basal ganglia).

Large samples of the population studied in the course of standardization of the Wechsler Adult Intelligence Scale (1955) indicated that there is a steady decline in cognitive function, starting at 30 years of age and progressing into the senium. All forms of cognitive function demonstrated decline although, certain elements of the verbal scale (vocabulary, fund of information, and comprehension) withstood the effect of aging better than those of the performance scale (block design, reversal of digits, picture arrangement, object assembly, and the digit symbol task) (9).

The aging *neuromuscular system* is of most interest in the post-polio syndrome. Tomlinson and Irving have provided evidence that the motor neuron pool is stable until approximately age 60. Thereafter the motor neuron population diminishes. In some cases motor neuron numbers may decrease to 50% of the middle life count (10). There is also reduced terminal sprouting (11,12). In individuals over 65 it is not uncommon to see fiber type grouping (unpublished observations) which supports the observation of motor neuron dropout.

In addition to the alterations in the motor neuron there is change in muscle. It is observed that there is loss of muscle mass with aging (13). This loss will cause increased use of the remaining muscle for activities of daily living and, subsequently, may further stress those motor units already at the threshold of maintaining performance.

THE MOTOR UNIT IN POST-POLIO SYNDROME

In people who had acute paralytic poliomyelitis there is electrophysiologic evidence that the motor unit is unstable. Fibrillation potentials, postive sharp waves, and fasciculations are observed in muscles of post-polio individuals who have no new complaints (14). These findings imply that the motor neuron is not performing normally. This instability can be demonstrated throughout the life of the polio survivor and worsens as the individual ages (15). These findings represent a continuous remodeling of the motor unit occurring at the level of the terminal nerve. As some terminal nerve/muscle connections are lost, the orphaned muscle may be reconnected to a terminal nerve from another motor neuron. A time comes when the disconnection rate overtakes the reconnection rate. Subsequently muscle

fibers are lost and new weakness begins. This critical threshold is more related to the time since the acute poliomyelitis rather than absolute chronologic age. New weakness that is noted at age 45 is a significant divergence from normal aging on two counts. First as noted, age-related motor neuron and terminal nerve loss are deferred until age 60. Second, in normal aging the weakness that accrues is subclinical.

It is the change in the motor unit which is at the heart of the post-polio syndrome and, in light of the observed electrophysiologic alterations in the motor unit, it is evident that the post-polio motor unit is not behaving as a normal aging motor unit. There are three possible causes for this altered performance.

1. The motor unit is expanded. Many motor neurons are carrying a greatly increased load of muscle fibers to compensate for those motor neurons that were lost during the acute poliomyelitis. It is uncertain if the cellular metabolic machinery can carry this increased load for a lifetime. Those motor neurons that escaped from acute poliomyelitis uninjured may be injured later by this chronic increased load.

2. Not all surviving motor neurons escaped uninjured. Many neurons showed evidence of injury but subsequently recovered (16). These motor neurons may have an unpredictable lifetime performance and especially be unable to support an expanded motor unit.

3. Motor units are stressed by an increased demand for firing. It has been demonstrated that the select muscle groups are greatly overused (17). The motor neurons controlling the motor units within these muscle groups are also overfiring. This may have a long-term damaging effect.

AGING AND POST-POLIO SYNDROME

I do not wish to imply that aging is not a factor in post-polio problems. Certainly the length of time a motor neuron carries an increased burden is critical. But it is the aging process itself that underlies the tendency of cell function to be less effective over time. There is something inherent in the youth of the neuron, or something lost with cell aging, that allows a young motor neuron, injured or uninjured, to be capable of handling an expanded muscle fiber population.

Immunologic findings in post-polio syndrome may or may not be related to aging. These findings may include: an increased CD4/CD8 (helper/suppressor) ratio (18), an immune activation where unexpected, a MHC class I expression in muscle, and an infiltration of muscle with lymphocytes and macrophages. Spinal cords of survivors who had poliomyelitis examined years after the original injury revealed mild perivascular and intraparenchymal inflammation. Some have also revealed oligoclonal bands in the cerebral-spinal fluid (16,19). These observations are consistent with an upregulation of immunologic function, possibly an autoimmune action. If an autoimmune process is present, this is in keeping with

the observation of increased autoimmunity with aging.

There is a slow multisystem decline in aging which becomes a factor but is not the cause of post-polio syndrome. For example, increased cardiopulmonary demands that have always been present due to a sub-optimal gait or body mechanics become more critical as age encroaches on cardiac and pulmonary reserve. Decreased pulmonary reserve due to scoliosis crosses the threshold and becomes functionally limiting due to loss of lung elasticity and diminished ventilatory capacity of aging. These changes of aging would have been silent in a similar aged individual who never had paralytic poliomyelitis.

In summary the physiology of normal aging is a slow multisystem decline. Post-polio syndrome is a more rapid oligosystem decline (neuromuscular). The divergence in performance of the post-polio syndrome individual from the course of normal aging represents a distinct pathophysiology. However, the pathology of aging likely plays a role in the emergence of the post-polio syndrome.

POST-POLIO SYNDROME AND AGING: CLINICAL FEATURES

In normal aging there is loss of muscle mass (13); some may be due to disuse. The loss of strength does not usually become functionally meaningful in the healthy elderly. Modest osteoarthritis produces only minor disability. The cause of greatest decline in performance is due to change in central motor control. The average

Table 1

Aging	Post-Polio Syndrome
1 No polio history	Old paralytic poliomyelitis
2 No residual biomechanical disadvantage	Residual biomechanical deficit
3 Mild diffuse loss of muscle mass, little functional impact	Focal moderate to severe loss of muscle strength and muscle mass with significant functional impact
4 Mild to moderate nuisance fatigue	Moderate to severe disabling fatigue
5 Cardiovascular, pulmonary, or cerebrovascular diseases most prominent	Neuromuscular complaint most common
6 Slow imperceptible decline in multiple systems	Slow to moderate decline in neuromuscular performance
7 Symmetric osteoarthritis	Assymetric osteoarthritis

individual also complains of some loss of productivity and decreased stamina. In disease-free aging, there is a gradual, almost imperceptible decline in function due to the combined effects of declining cardiopulmonary capacity, muscle strength, central motor control, and accumulating osteoarthritis.

The post-polio person also experiences these changes, which may be noted at a much earlier age (45 vs 60). Change is also much more dramatic than seen in normal aging. Loss of muscle strength is focal; if multifocal, it may lead to marked disability. The fatigue and loss of stamina is profound and disabling as opposed to a nuisance in normal aging. The osteoarthritis seen in the hips and knees of an individual with abnormal gait may also be profound.

In practice, the post-polio person stands out from the average geriatric center individual on several counts (Table 1). Polio survivors are usually 10 years younger. Their symptoms are more constrained to new weakness

and fatigue indicating an oligosystem (1 or 2 system) failure vs multisystem failure. A typical geriatric patient has one or more medical problems. For example, a prior pneumonia and cardiac disease is a common combination. A modest fatigue is sometime present, but is accounted for by a clear medical problem. Profound fatigue is uncommon. A complaint of specific focal new weakness is even more uncommon. Thus the post-polio survivor with

Table 2. Post-Polio Syndrome vs Aging: Interventions

Goal	Aging	Post-Polio Syndrome
Maintain muscle strength	Strength training	Modified non-fatiguing, paced strength training of affected extremities
Cardiovascular fitness	Aerobic exercise	Modified non-fatiguing aerobic exercise
Increased stamina	Exercise and activity	Carefully meter physical activity
Optimum physical performance	Physical therapy to involved areas. Orthotic and assist devices	Physical therapy in the form of muscle training only in special situations. Orthotic and assist devices as needed.

continued on page 6

their defining features usually stands out on this basis alone.

POST-POLIO SYNDROME VS AGING: INTERVENTIONS

Interventions to promote neuromuscular and cardiovascular fitness are different in the post-polio and general population (Table 2). Increasing muscle strength may be accomplished by conventional techniques of muscle training constrained only by the cardiac and orthopedic status of the individual. An otherwise healthy elderly individual may enter graduated weight training. As their training progresses they are able to increase their limit to produce a modest degree of soreness and fatigue. This approach would be deleterious to a post-polio survivor. In short, the training principles for the geriatric population are parallel to those of the younger adult population with allowances made for baseline cardiovascular and joint condition. In the post-polio individual there must be no residual pain and minimal fatigue after training. Some post-polio people are unable to pursue cardiovascular or strength training due to extensive motor neuron and attendant muscle loss. □

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"I probably am your oldest subscriber.

I had infantile paralysis in 1923 when I was 18 years old. I was traveling with my parents (camping, of course). Doctors had no idea why I had such a high temperature, was so miserable, and could not move my arms or legs without help. One suggested they put me in the "Fischer's Hot Mineral Springs," a rack-constructed tank about the size of a small swimming pool and help me move. It was in Eastern Oregon, near Haines, and only a couple of miles from my uncle's place, where we had expected to spend a month. This they did almost every day and although I improved, I had to have help to get up, dress, walk, and even to turn in bed.

Several months later we learned of a death from infantile paralysis in Missoula, Montana, where we had spent time prior to my illness. The doctor who later examined my still partially paralyzed legs at home in California said no doubt I had infantile paralysis. It was years before I discovered how lucky I was to receive the right treatment at the right time.

Now the weakness, paralysis, and cramps have returned, and x-rays show degenerative osteoarthritis of the left hip joint, although I have no other indication of arthritis in any other part of my body. I am 91 years old. I still walk with a cane or walker, handle my own business, and ask for no special help at the retirement home where I live.

This is why I want to be informed of current developments which hopefully will be discovered about post-polio syndrome. Thanks for your help."

Irene, California



Sixth International Post-Polio and Independent Living Conference **LIVING WITH DISABILITY**

JOYCE ANN TEPLY, LMSW/ACP, LPC

Board Certified in Clinical Social Work, Dallas, Texas

I was nine years old when I got polio. It was the summer of 1952. A few days later my brother, who was only eight months old, was also admitted.

At the time, I had no idea how difficult the whole ordeal was for my mother and father. They never showed me the fear they had that I would not be able to walk. They protected me from their financial worries. They were always encouraging. They made enormous sacrifices in time and effort, driving for two hours each day they came to see me. They did not want me to feel neglected. Over the years I have received much recognition for what I have been able to do with my life "despite my disability," but the unsung heroes are my parents.

By the spring of 1953 the hospital had done its job well, and I was ready to go home. For the first time since the day I got polio I was scared. Though my family did everything they could to help me adjust to my new physical limits but still live a full life, I struggled for a long time with a strong feeling of not being good enough. I felt different and damaged. Though my physical rehabilitation was impeccably good, little attention was paid to my feelings. I remember being continually complimented about my brave smile and cheerful disposition. Only my diaries knew how depressed and ashamed I felt. I was different.

While I was trying to learn to walk without my braces, my brother was learning to stand up using my wheelchair pedals for support. We were expected to do chores. A good education was emphasized and provided for. Our parents did not want us to go to a "special" school for "crippled children." They wanted us to deal with real life situations, not to be too sheltered. In retrospect, I am grateful for the sound education I was given, but there was also a high expectation put on me to develop my mental abilities since I did not have a strong body.

Each year my mother participated in the Mother's March in our neighborhood. One of the services provided us was two weeks at Camp Cheerful during the summer. I went when I was fourteen and fifteen. It was the highlight of my childhood and the beginning of my adulthood. So much of my adolescence I was haunted by feelings of inadequacy and lack of self-confidence. But at Camp I felt normal.

I went a thousand miles off to college. It was a big risk to go away so far to college, but my parents continually encouraged my independence. I graduated with a degree in social work. I went on to graduate school in Texas and in 1967 started my career working for a mental health clinic in Dallas.

From age 15 until my early 40s I have been stabilized in my disability. I have tried to think of it as merely an inconvenience. I was active in the disabled rights movement as president and founding board member of our Dallas center for independent living. Through that experience I learned to take pride in myself as a disabled person. □

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JOYCE ANN TEPLY'S TEN AXIOMS FOR LIVING WITH POLIO

1. Approach one's life from the inside out.
2. Anything one does physically comes from an idea first.
3. Work with intention rather than will power.
4. Attitude is more important than activity.
5. An attitude is an idea blended with emotion. It is the most powerful energy in the world.
6. One can profit from a negative attitude just as from a positive attitude. It does not matter as long as one has an attitude of learning.
7. Living is a process, not a goal.
8. Living well depends more on how one learns from one's experiences rather than on what one accomplishes.
9. Wisdom is a truer measure of one's worth than how many things one owns or how much one does.
10. To be discovered within the next 30 years.

"I am in my 40's and wear shoes of two size groups (13 1/2D child's shoe, 6 1/2B or 7B woman's shoe). I am searching for shoe companies which make the same style/color in these two size groups or for recommendations regarding companies or individuals who make custom shoes which would accommodate various orthopedic modifications. I would also like to know whether others have had success in receiving authorization or payment from insurance companies for custom shoes."

E. M. Kief, New Mexico

Please send your comments and suggestions to International Polio Network.

Pedorthics (ped-or'-thiks) is the design, manufacture, modification and fit of shoes and foot orthoses to alleviate foot problems caused by disease, overuse, or injury. A certified pedorthist (C.Ped.) is a professional whose competence has been tested and established by the Board for Certification in Pedorthics, the independent agency that sets the nation's pedorthic standards.

To find a board certified pedorthist (C.Ped.) in your area, write or call Prescription Footwear Association, 9861 Broken Land Parkway, Suite 255, Columbia, Maryland 21046-1151 (410/381-7278, 800/673-8447, 410/381-1167 FAX).

This was the "billionth" pair of brown saddle oxfords that Lynda, my wife, purchased. Why would she wear those particular shoes every day of her life to the exclusion of all others? She went to church in brown oxfords that went nicely with her pants suit. She went on picnics in jeans and a sweatshirt and brown saddle oxfords. We went hiking through the woods — me in my sneakers and Lynda in her brown saddle oxfords. At our wedding she wore ...

Lynda's shoe selection is limited because the right foot requires a child's shoe with a three-inch lift and the left foot requires a woman's shoe. The left and right shoe really should match.

Since I do not need a lift and can wear whatever shoe I want, I regret to say I was a little slow to see things from her point of view. I found her attitude toward the orthopedic profession unusual. She was surly at times and was always skeptical. I now understand.

I now understand what it would feel like to be a maturing young person, interested in the opposite sex, attending a party where all of the girls are taking the risk of wearing high heeled shoes in public for the first time. I think I understand how it would feel to arrive at the party with shoes, selected by someone else, with all the stability, charm, and style of a concrete block.

It seems that the people who could help Lynda the most wanted to control her choices and remove all risk from her life. We all face risk every day and each must make individual and well-considered choices. Choosing what is and is not an acceptable risk should involve the advice of qualified professionals, but the final decision should be our own.

After some professionals hesitated (even refused) to make a lift for hiking shoes because "you do not want to do that, hiking can be dangerous," I was in complete sympathy. I was determined to help her wear whatever shoes she wanted and to encourage her to do all that she could do. I bought and experimented with solvents and glues; bought tools and made up processes. It took a while but I perfected a process that works on any shoe except one with a gum sole. I have been making the lifts for Lynda's shoe for more than ten years now. At our son's June wedding she wore a pair of white sandals with her color coordinated mother-of-the-groom dress. I was by her side all the time. She probably would have been safer in brown saddle oxfords, but she looked and felt beautiful.

If you need a lift on a shoe and your regular source will not or can not do the work, I may be able to help you. To make preliminary inquiry, send a description of your shoe and lift to David Scaggs, 902 Shadow Creek Drive, Stockton, California, 95209 (209/477-6880). Please be sure to include you telephone number.

EDITOR'S NOTE: Any business transactions resulting from this article are the responsibility of those involved, not I.P.N.

RESOURCES:

National Odd Shoe Exchange
7102 North 35th Avenue, Suite 2
Phoenix, Arizona 85051
(602/841-6691; 602/841-3349 FAX)

Non-profit that assists amputees and people with different size feet.

One Shoe Crew
86 Clavela Avenue
Sacramento, California 95828
(916/364-7463)

For a fee, the service registers individuals who want to find a shoe partner.

Tru-Mold Shoes, Inc.
49 LaSalle Avenue
Buffalo, New York 14214
(800/843-6653; 716/837-3867FAX)
Will manufacture shoes from casts.

ACOR® Orthopaedic, Inc.
18530 South Miles Parkway
Cleveland, OH 44128-4238
(800/237-2267)

Will manufacture shoes from casts, etc.

Hitchcock Shoes, Inc.
225 Beal Street
Hingham, Massachusetts 02043
(617/749-3571; 617/749-3576FAX)

Specializes in extra wide shoes;
free catalog.

Tru-Fit
500 Fifth Avenue
Pelham, NY 10803
(800/348-7662)

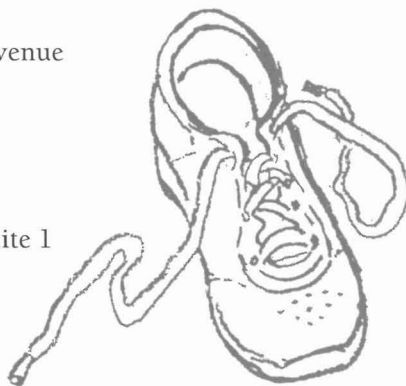
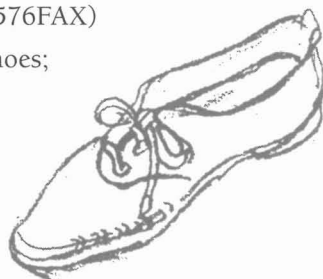
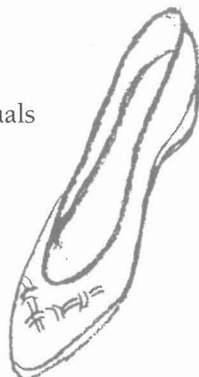
Call for a free catalog.

***The following were recommended by polio survivors.
Please send your recommendations to be listed in the
next issue of the Polio Network News.***

Vince's Shoe Service
Vincent Sgro
182 East Tallmadge Avenue
Akron, Ohio 44310
(216/762-4331)

and

Ernesto Castro
835 East Southern, Suite 1
Mesa, AZ 85204
(602/926-4130)



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A yearly subscription to *Polio Network News* is \$16.00. Renewal notices are sent six times a year — in February for January and February; in April for March and April, etc. The renewal month on the label (of our readers in the States) is the same as the month we receive the payment. Readers who move from north to south and back again are requested to contact us each move. We will make sure you do not miss an issue.

We continue to receive a considerable amount of mail addressed to our *old* address. If we are on your mailing list, please check our address:

4207 Lindell Blvd., #110
Saint Louis, Missouri 63108-2915 USA

314/534-0475
314/534-5070 Fax
gini_intl@msn.com

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Aquatic Therapy

FOR POLIO SURVIVORS

Members of the Northwestern Post-Polio Support Group benefit from participating in an aquatic therapy program in Rehabilitation Institute of Chicago's (RIC) newly remodeled therapeutic pool. In the Chicago, Illinois, metropolitan area, few therapeutically-heated (90° or higher) pools are available for independent exercising. They are used only for physical therapy purposes.

It is generally thought that for polio survivors with cold intolerance and weak muscles, warm water allows exercise that is safe and beneficial. Linda Bieniek, one of the coordinators of RIC's post-polio pool program, became convinced "after working with a physical therapist and exercising in a therapeutically-heated pool. I came out feeling refreshed and noticed that, with time, my energy and breathing improved."

Bieniek and Barbara Black, a polio survivor who works as RIC's patient services administrator, tackled the problems of access, liability, and cost. With the support of James Sliwa, DO, coordinator of RIC's post-polio clinic; Michael Minieka, MD, a neurologist at Northwestern Medical Center; and Kathy Martinez, a physical therapist at RIC; the support group gained access to the pool.

A grant from a private foundation covers about 50% of the expenses with participants paying the remaining costs. Most attend twice a week and pay quarterly to qualify for a discount. Expenses include wages of a staff person and laundry costs.

Most members free swim while a few only exercise. Although a staff person is available to assist in an emergency, the program is intended for independent exercising and swimming. Each person is encouraged to develop an individualized program with the assistance of his or her physician and physical therapist. All participants are required to review a discussion of policy and procedures and sign a legal waiver.

After the RIC's pool program began, Bieniek read in the June 1995 *Rehabilitation Gazette* (Vol. 35, No. 2), about a video designed specifically for polio survivors which was developed under the direction of Robbie B. Leonard, MS, PT, Director of Therapy Services, Roosevelt Warm Springs Institute for Rehabilitation, Warm Springs, Georgia. The group ordered the video and incorporated it into their orientation program.

Participants in the pool program have found the video useful because it: emphasizes the need for each person to individualize his or her exercise plan in conjunction

with one's physician; stresses the need for "warm up" and "cool down;" "identifies "danger signs" (e.g., pain) that indicate a need to reduce or stop the amount of activity and to consult one's physician; includes some simple exercises and suggestions.

Many participants requested handouts to illustrate the exercises demonstrated in the video, and they were not available at that time. Since then, Leonard has developed an eight-page booklet entitled "Pool Exercise" which now comes with the video.

According to Leonard aquatic therapy is beneficial to polio survivors because movements can be performed with less energy in the supported environment; stretching, strengthening, and endurance activities can be done; the heat may help with pain relief. She suggests that aquatic therapy be done during the "good" time of the day and stresses that any program should be individualized. When choosing an aquatic program look for an accessible environment, a non-slip deck, warm water (85° to 90°), warm air temperature, a pool monitored at all times, and a program which allows modification or individualization. □

For a copy of

Aquatic Therapy for Polio Survivors

and the accompanying booklet *Pool Exercise* send \$29.99 (includes shipping and handling) to: Roosevelt Warm Springs Development Fund, Inc., P.O. Box 1050, Warm Springs, Georgia 31830-0268. Please make your check payable to the "Roosevelt Warm Springs Development Fund, Inc." For income tax purposes you may consider \$15.00 as a donation. The Development Fund is raising money to renovate the historical part of Roosevelt Warm Springs. They are currently working on Georgia Hall and are raising funds to renovate Roosevelt Hall.

RESEARCH TO START IN EARLY SUMMER

As reported in *Polio Network News* (Vol. 11, No. 3), the Department of the Army awarded a grant to Albert Einstein Medical Center and MossRehab Hospital in Philadelphia, Pennsylvania, to study the muscle overuse syndrome in individuals with prior polio. It is thought that musculoskeletal pain and injury sustained by individuals with weakness from polio may serve as a model for the type of overuse injury that military recruits with normal strength experience from greater physical demands.

The project, directed by Drs. Mary Ann Keenan (orthopaedics), Alberto Esquenazi (physiatry), and John Whyte (physiatry), will study about 300 individuals with polio. Each participant will be seen four times over a one-year period, to have their strength measured and to see whether and where they have any musculoskeletal complaints or symptoms. Several smaller studies are linked to the larger study, in which individuals with particular problems with pain or weakness will be offered experimental treatment protocols involving plastic shoe inserts or bracing, strengthening exercise, or training in activity modification. Individuals with symptoms that do not fit the experimental treatment protocols will be offered clinical referral into the post-polio clinic if they desire.

The project aims to predict individual's susceptibility to muscle overuse injury based on their pattern of weakness and to develop ways of preventing and treating these overuse injuries. In order to be eligible, participants must have a history of polio with some remaining weakness but need not have current musculoskeletal symptoms. They must be willing to visit the project site (Philadelphia, Pennsylvania) at least every four months. Nominal payment for research participation will be made. Enrollment of research participants will begin in early summer.

Interested participants should contact ...

the Post-Polio Project, Moss Rehabilitation Research Institute, Korman Bldg., Suite 213, 1200 West Tabor Rd., Philadelphia, Pennsylvania 19141 (215/456-4993, FAX 215/456-9514). □

BRAILLE LITERATURE

Thanks to Midwestern Braille Volunteers, St. Louis, Missouri, the brochure ***Late Effects of Polio — An Overview*** is available in Braille. Contact International Polio Network to request a copy.

POST-POLIO BIBLIOGRAPHY

Lack of progression of neurological deficit in survivors of paralytic polio: A 5-year prospective population-based study by Anthony J. Windebank, MD, William J. Litchy, MD, Jasper R. Daube, MD, and Rita A. Iverson, RN; *Neurology* 46, January, 1996, pp. 80-84.

Article abstract ... We completed a prospective, population-based cohort study of polio survivors in Olmsted County, Minnesota between 1986 and 1993. We identified 50 individuals who had had paralytic polio between 1935 and 1960, as representative of all 300 cases of paralytic polio in the county. We completed detailed quantitative clinic and electrophysiologic study at entry and after 5 years. These studies demonstrated stable neuromuscular function within the cohort, although 60% of the individuals were symptomatic. In two-thirds of the symptomatic patients, the causes of their symptoms were unrelated to earlier polio. For the 20% of patients who had unexplained muscle pain, perception of weakness, and fatigue, a mechanical disorder most likely underlies their symptoms.



Post-Polio Syndrome ... The new face of an old enemy by Susan B. Millan, MD; Family Practice Recertification, Vol. 18, No. 3, March, 1996, pp 32-47.

A survey article written for physicians in family practice by the daughter of a polio survivor. □

THE BRAIN BANK

As mentioned in *Polio Network News* (Vol. 6, No. 3), the National Neurological Research Specimen Bank, commonly known as the Brain Bank is located in Los Angeles, California. The Brain Bank does not conduct research but does bank tissue (brain, spinal cord, and peripheral nerves) and distributes the tissue to researchers on written request. Participation in the program generally involves no expense to the donor family. Arrangements for tissue donation will be made by a representative of the Bank.

For information on how to enroll yourself, or your brothers and sisters to serve as controls, in the Gift-of-Hope tissue donor program, contact Iris Rosario, RN, MA, National Neurological Research Specimen Bank, W. Los Angeles, VAMC 127A, 11301 Wilshire Blvd., Los Angeles, California 90073 (310/268-3536; or 310/268-4768 FAX). □

NEW POST-POLIO SUPPORT GROUP

The former Kansas Post-Polio Support Group from southeast Kansas has combined with the western-most counties of southwest Missouri to form KAN DO MO, which will hold three meetings a year. The next meeting is scheduled for July 20 at 10 a.m. at the Oswego, Kansas, Public Library, 704 4th Street.

For more information write or telephone: KAN DO MO, c/o Ina Mae Brooks, Independent Living Center, 2650 E. 32nd Street, Suite 102, Joplin, Missouri 64804 (417-659-8086). □

MEMORIAL DEBATE

The Franklin Delano Roosevelt Memorial is due to open in the Spring of 1997 on the Tidal Basin near the Jefferson Memorial in Washington, D.C.

The National Organization on Disability (N.O.D.) requested more than a year ago that the Franklin Delano Roosevelt Memorial Commission change the proposed design to more clearly depict President Roosevelt's disability and the fact that he spent most of his adult life using a wheelchair and leg braces.

The Commission defends its design which effectively hides FDR's disability because to do otherwise would be historically inaccurate. They feel the monument should not make a public display of what FDR himself hid in his lifetime.

To express your opinion, write to:

Dorann Gunderson, Executive Director
Franklin Delano Roosevelt Memorial Commission
Hart Senate Office Building
Washington, DC 20510

or

President Bill Clinton, Honorary Chairman
(same address)

Calendar

— 1996 —

Post-Polio — A Complete Overview, June 21-23, Daytona Beach, Florida.

Contact: Barbara Goldstein, Florida East Coast Post-Polio Support Group, 12 Eclipse Trail, Ormond Beach, FL 32174 (904/676-2435).

Living with the Late Effects of Polio, November 8-10, Sydney, Australia.

Contact: Post-Polio Network (NSW) Inc., P.O. Box 888, Kensington, New South Wales 2033, Australia (612 636 6515).

Post-Polio Syndrome: It Can Take Your Breath Away, November 9, Ocala, Florida.

Contact: Carolyn Raville, North Central Florida Post-Polio Support Group, 7180SW 182nd Court, Dunnellon, Florida 34432 (352/489-1731).

— 1997 —

G.I.N.I.'s Seventh International Post- Polio and Independent Living Conference, May 28-31, 1997, St. Louis

Marriott Pavilion Downtown.

Please send your suggestions for topics which need to be discussed to:

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