# POST-POLIO NETWORK (N.S.W.)

## NEWSLETTER NO. 2

## MARCH 1989

The Editor,
P.O. Box 4055,
Parramatta 2150

Our second newsletter is a brief note taken from the minutes, to keep you informed about what is happening with the Network.

### Incorporation

It was resolved by the Work Party that the Network should be an incorporated body and that steps should be taken to achieve this.

### Name

It was resolved that the name should be Post-Polio Network (N.S.W)

### Constitution

A draft constitution is being prepared for presentation at the First General Meeting of members - Inaugural meeting - Post-Polio Network (N.S.W.) on 18th March, 1989.

The Working Party elected an Interim Committee.

### Office Bearers:

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| President | Laurie Alsop |
| Vice-President | Pat Rich |
| Secretary | Terri Fletcher |
| Treasurer | Gwen Tubb |
| Publicity Officer | Angelo Psomadelis |

### "Post-Polio Survivors and their Health"

Thankyou to all members who have filled out this survey. About 80 surveys have been returned. If you have not yet done so, please do, as the information is needed to gain a picture of what is happening to people in Australia, who have had polio. It doesn't matter if you can't answer every question. Many people may have been too young to remember the early phases. Just fill in what you can remember, particularly details about current symptoms. If more copies of the survey are required,please contact the Network.

### Constitution

A draft constitution has been prepared for adoption at the inaugural meeting and initial steps taken towards incorporation.

It was noted that media coverage on the Post-Polio Syndrome in Womens Day and on 2UE had resulted in many more people contacting the Network.

### Resource List

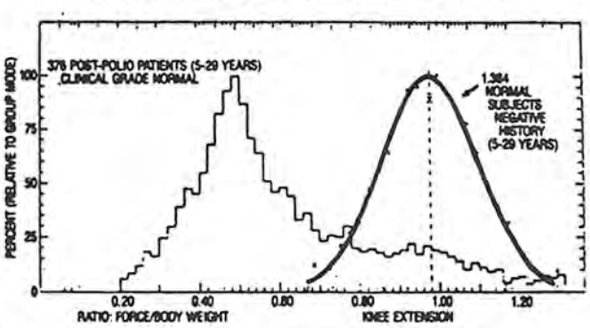
It was agreed that a Resource List of doctors and physiotherapists with an interest in and/or knowledge of polio, should be compiled and published in future editions of the Newsletter. If you know of any doctors or physiotherapist who could be on the list, please let us know.

The following articles are taken from the Proceedings of Gazette International Networking Institute's Third International Polio and Independent Living Conference - 1985. The Conference dealt with various aspects of the late effects of polio: exercise; respiratory support; pain management and polio research. We will publish a number of these articles in this newsletter

Physical therapists have long known how critical the application of strengthening exercises were for polio patients. Even in the chronic stage where we were using resistive and repetitive exercises to increase the size of muscle fibers and to encourage the sprouting of nerve fibers, exercises were monitored carefully to avoid loss of muscle strength. Muscle testing was done at every treatment, even though it wasn't recorded. If a decrease in muscle strength occurred, there was too much activity or exercise. We would change our focus and give that muscle group or muscles less activity and concentrate on another area. Plateaus were warnings to be careful or the message that the maximum amount of strength had been gained. This occurred at nine to twelve months from onset.

Even though by muscle testing a muscle could take maximum resistance, and was graded a 5, or normal, the muscle could have lost up to 50% of its nerve cells (Sharrard 1955). Clinically this was also demonstrated by Beasley's work as shown in Figure 1 on quantitative muscle force testing (Beasley 1960). Normal subjects were tested for the pounds force the quadriceps muscle could exert and compared to the force produced by patients with post-poliomyelitis who had a muscle test grade of "normal". It was found that few of the post-polio muscles were in the normal range and they averaged 50% less in strength than normals.

**Figure 1**
**KNEE EXTENSION**
**QUANTIFIED SCALING OF PARESIS**




***Ratio of knee extensor force and body weight in normal subjects and post-polios with a muscle test grade of 5 or N. (Adapted from Beasley 1960).***

Functionally, over these many years, the weak muscles have been called upon to perform at high levels of their capacity. Strong, or truly normal, muscles have also been called upon to do a bigger job in order to compensate for other muscle losses. As the new problems developed in many people, they turned to exercise — weight lifting, jogging, aerobics, or swimming. Exercise helped at one time, but now they reported that instead of gaining strength, their problems were becoming worse. In many of the people that we evaluated, the muscles seemed exhausted. Their contraction was of a poor quality. They had a hesitancy to want to contract. They cramped easily. Some of them twitched at rest or in activity.

Rather than adding to the burden of the work load of these weak muscles, or overworked normal muscles, we have sought to decrease their burden by trying to get the body operating in a more normal and efficient manner with less use of muscles, and therefore with less use of energy. In sitting, standing, or walking, the normal body uses very few muscles at a low level of their capacity and provides the muscles with brief and frequent rest periods. To do the same activities, however, the post-polio must use more muscles, at a higher level of their capacity, and frequently without permitting periodic rest periods.

Our greatest initial success has been in restoring the erect position with better seating. People are sitting for hours per day in a slumped position in desk chairs, dining chairs, cars, or in wheelchairs that are not supporting the lumbar spine. We have been using lumbar rolls, balance chairs, corsets, and secretarial chairs to restore the lumbar and cervical curves. This in turn decreases the constant muscle contraction in the neck, shoulders, and back; hanging on ligaments; and pain from these sources.

In standing, the principles are similar. We work to gain weight-bearing through bony support, or through orthotic support, rather than through muscular contraction. For example, people with a stronger leg have probably spent most of their lives bearing most of their weight on this leg which requires continuous muscle contraction at a higher level of muscle capacity. If the person was an amputee, we would be concerned about getting a prosthesis so that the good leg did not wear out. With a post-polio, frequently a heel lift, a short orthosis or correction of their current orthoses permits the weak leg to bear its share of weight and reduce the work of the stronger leg.

In walking we work to gain the erect position and to decrease abnormal movements which increase energy expenditure. Many people are looking at the floor as they walk because they are afraid they are going to trip, their knee is going to buckle, and they are going to fall. This slightly flexed position causes continuous and abnormal back muscle contraction and, eventually, pain. By taking away the need to look at the floor through use of orthoses to pick up the toe or stabilize the knee, the person can become erect and eliminate the continuous contraction and overuse of muscles with resulting decrease of pain.

Although we are not advocating strengthening exercises, improved alignment in sitting, standing, and walking, along with decreasing non-essential muscle activity has decreased pain and fatigue and provided a sense of increased muscle strength. For ongoing exercise programs, we are recommending beginning Yoga, relaxation exercises, pool exercises done easily, recognizing that a muscle can be exhausted in water just as easily as on land. Exercises of body awareness and movement such as the Feldenkrais exercises or Tai Chi are reported by many as providing a feeling of well-being and improved function.

The rationale for treatment of pain problems from degenerative changes secondary to poliomyelitis begins with prevention. Prevention can only be effective if one understands the natural course of the disability that has brought about these changes and induced a pathologic sequence of destructive change. Therefore, the hallmark of prevention and treatment is, first of all, centered around joint protection. This requires insight and education of the physician, therapist, and the person with these post-polio changes. A healthy understanding of the change of kinesiologic forces (those of muscle function), and their alteration is important. Enhancing repair of these changes depends on good nutrition, good blood supply, reduction of swelling and inflamniation, and weight reduction.

I mention the matter of weight reduction as many post-polio patients find that as muscle mass is reduced, so is energy expenditure. Therefore, a relative caloric excess is present which promotes obesity in the post-polio person and adds to the wear and destruction of the joints.

In certain circumstances, the actual deposit of fat adjacent to some spondylitic or hypertrophic neural foramina in the cervical or lumbar spine can add to the compromise of the nerve. With added pressure, more inflammation and swelling is present, there is less effective circulation, and diminished nutrient repair. Hence, there is more pain and destruction. A "dog with its tail in its mouth" condition exists, and the problem keeps going around in a circle.

The post-polio person often uses the head and neck to lever the torso when in bed or against furniture for assisted movement or balance. Degenerative changes occur from excessive activity, and spondylitic or hypertrophic degenerative changes occur about the vertebral bodies and articulating facets. This results in these joints between the vertebral bodies producing spurs and bony overgrowth. I have seen many people doing this, working their way across the bed. A great deal of excess movement and body force is therefore placed upon the cervical spine. In addition there occurs degeneration, often producing direct nerve pressure, or the development of foraminal compression syndromes on the nerves that leave the spinal cord. Dr. Maynard has just referred to these nerves.

One often feels a grating sensation with or without pain in the neck or radiating into the arms and hands, and up into the head. Pain may cause reactive muscle spasms. The prevention, insofar as possible, is to avoid or minimize using the head and neck for leverage. The treatment utilizes, first of all, moist heat packs to the neck for muscle spasms to transiently increase local circulation.

Second, the use of a cervical traction device, such as over-the-door, or bed clamp-on traction devices, and with a weight bag. Water or sand is placed in the bag. The weight in the bag should be greater than the weight of the head. The weight of the head is normally seven to nine pounds. It is desirable to gradually increase the weight up to as much as ⅛ of body weight for 20 to 30 minutes once or twice a day. When the weight exceeds twice the skull weight, there will often be an uncomfortable pressure on the jaw and teeth and most individuals will not tolerate more than 16 to 20 pounds.

The third treatment mode is body weight reduction to 10 to 20% below norms for those with moderate to extensive muscle loss. In other words, when one loses muscle, one loses a lot of tissue, and the normal weight with that muscle tissue would be lower than the norm. I prefer for simplicity and reasonably well-balanced nutrition to recommend the methods of Nathan Pritikin.

Anti-inflammatory medications, Tylenol or Ibuprofen, or, as Dr. Maynard has alluded to, Motrin or Advil, in 200 to 400-milligram tablets can be taken with or after meals and at bedtime with milk.

Sleep with a thick but comfortable pillow when on the side, so that the head is in a straight line with the body. Many pillows are very soft, but the head drops to one side of the pillow, and accentuates some of the compression problems. I turn the pillow on the side instead of flat, and clear the shoulder. If one sleeps in a prone position, get rid of the pillow altogether. In the supine position, have the pillow flat or low, slightly flexing the neck.

The next treatment consideration is occasionally the use of a soft surgical collar or Philadelphia collar that may help, if muscle spasm is acute. All orthotic devices are a two-edged sword and can, by prolonged splinting, facilitate muscle weakness.

Degenerative changes in the shoulder are usually present in, first, the glenohumeral joint (the main shoulder joint articulation, the ball-and-socket of the shoulder) or secondarily, the acromioclavicular joint. The degenerative process of the former is usually the result of weight-bearing, such as crutch walking, or of swinging transfers, such as wheelchair to bed, toilet, car, etc. This weight-bearing, for which the shoulder was never intended, may also produce many soft tissue complications, such as the rotator cuff syndromes with inflammation, bursitis, ruptured tendons, such as rupture of the supraspinatus tendon with attendant loss of range of motion, periarticular muscle spasm, and progressive disuse.

Prevention may require changing swinging transfers to sliding board transfers or modification of crutch walking techniques. Exercise, per se, is not the culprit, but rather the loading forces. Therefore, try to unload, and try to substitute. In spite of the destruction, I believe that nonresistive active exercise, such as swimming or wheelchair mini-marathon workouts where physical condition permits, are all desirable, as blood is brought to the joint by this activity and assists in repair.

It usually takes a period of 20 to 30 minutes of continuous exercise to be effective, and one must work through a certain amount of stiffness and pain. A preliminary stretch or workout is effective and often must be repeated at intervals during the workout, such as pendulum exercises.

If a more structured treatment program is necessary by a physical or occupational therapist, then I suggest short-wave diathermy or ultrasound, such as Dr. Maynard has alluded to, as the heat modality of choice for the shoulders, hips, and knees. These modalities will promote an increase of the deep circulation better than moist heat.

Many find sleeping on one side adds to pain; therefore, I have found that the double-pillow technique which I've mentioned is often beneficial here. Use of anti-inflammatory medications may also be of benefit in these conditions, and seems to be most effective when the pain is aggravated by a falling barometer. Many have noted that, and feel better when the barometer rises. That's physiologically sound, because of the intercellular-extracellular fluid compartment shift, and particularly among fibrous connective tissue which does not respond well to intercellular fluid changes.

With respect to degenerative changes in the acromioclavicular joint, there is probably little that is effective other than symptomatic relief through heat and anti-inflammatory agents. Often the destroyed joint will spontaneously fuse and stop the motion that created the pain. Fusion will reduce the range of motion in internal and external rotation of the shoulder in hyperflexion and hyperabduction. If, after time, the problem is not resolved, sometimes a resection or osteotomy may be considered, but then one may put up with a free-floating clavicle, at the distal outer end. Some find that a problem.

Notice that in Dr. Yarnell's statistics, as well as some of my own studies with Dr. Rawlings at the University of Western Australia (which we presented at the American Spinal Injury Association 1981), and finally by the studies of P.J.C. Nichols at the Nuffeld Orthopedic Hospital, and the Mary Marlboro Lodge of Oxford, England that problems of destructive changes in the elbow are almost non-existent. It is true that tardy ulnar palsy often exists, and Dr. Maynard and Dr. Yarnell referred to that, but one rarely finds degenerative changes in the elbow.

In the wrist and hand, there is occasionally destruction of the radial-ulnar joint, and occasionally of the small carpal joints like the navicular, the lunate, and the pisiform joints that provide that articulation of the wrist. However, the most frequent sign of destruction is the destruction between the metacarpal and the carpal joints at the thumb. This is frequently in wheelchair users who are pushing their own chairs, and it exists because of the repetitive hammering of the thenar eminence of the hand. It also produces a carpal tunnel syndrome. It is a major problem particularly in wheelchair athletes, and individuals who are very active in their wheelchairs.

The treatment and prevention are almost the same. Where extended activity is undertaken, use bicycle or sailing gloves. Bicycle gloves are cut off at the proximal interphalangeal joint; the sailing gloves are cut off at the distal interphalangeal joint. These gloves should be slightly too large, and one should insert a foam rubber pad, sorbithane, or other polyurethane gel pad, or artificial fat, such as Spence Gel, under the palmar side of the glove, and over the wrist and thenar eminence. This will often alleviate the problem.

A good joint protection program outlined by physical therapists is highly beneficial. Regional heat, such as a pan of hot water, or use of a paraffin bath, can also be helpful. Splinting of the interphalangeal joints, that is, in the fingers, with IP stablilizers will be helpful in many individuals, and of course, the medication situation previously described is applicable here.

In the lower extremities, the weakened, imbalanced musculature, and what I call "Indian" weight gains (weight gained that keeps creeping up on you), are responsible for hip, knee and ankle problems. If one has been accustomed to walking without aids, then resorting to their use will be highly beneficial. The cane or crutch should be used in the opposite hand to spare the repetitive trauma. Symptomatic relief may be partially afforded by moist or deep heat, as previously mentioned, as well as the use of anti-inflammatory agents.

I have found that in those individuals who also have concurrent low back pain, the use of inversion traction or gravity suspension traction is often quite beneficial. Orthotic use will also frequently transfer the forces from the hip or knee to the pelvis. One must use lightweight materials. With the new advances of orthotics in polypropylene and polyethylene, metal joints may sometimes be eliminated. However, one of the greatest problems here is the psyche. A person will often compensate for years without an orthotic device, and then an illness will force recumbency followed by inability to substitute any longer.

The recurvatum of the knee, or the back knee, is destructive and painful. Use of a knee cage brace is rarely a satisfactory solution. They often must be so tight that they occlude venous circulation. I believe that a knee-ankle-foot orthosis (that is, a long-leg brace), is preferable, as the forces are transferred to the ground and weight-bearing is partially relieved. This is also true of the hip (and I have often resorted to the prosthetic principle of a modified quadrilateral socket) with ischial weight-bearing in a knee-ankle-foot orthosis, or the use of an ischial ring. This permits the pelvis to sit on the rim, and reduces weight-bearing across both the hip and the knee.

One must never forget the wisdom of Dr. Robert Bennett of Warm Springs, Georgia, when he said the ideal brace should weigh nothing, cost nothing, and be invisible.

Many other considerations may be entertained, to include surgical joint replacement in the hip, knee, and shoulder in diminishing order. The post-surgical period may be a trying one, and one may find the recovery period immobilizing for the post-polio as compared with other relatively able-bodied persons.

The problem of scoliosis is so complex I cannot offer simple remedies. It requires the most careful scrutiny and guidance by orthopedic surgeons, physiatrists, physical therapists, and others. Use of selected asymmetric exercises may be initiated under the therapeutic supervision of these professionals. Orthotic devices and surgical fusion are frequently necessary. Use of heel lifts to compensate for pelvic tilt when the cause is leg length discrepancy, is often beneficial.

Pain in the lumbosacrum from degenerative disease, such as a facet syndrome, is aided by heat and some exercise. Most of all, I find pelvic traction with a halter, using up to ¼ to ⅓ of body weight, is beneficial. Use of suspension, traction, or inversion traction is also often helpful. No one treatment is universally satisfactory. Many or all of the above remedies may be helpful.

## Thomas Gucker, 3rd, M.D.

It's been estimated most recently that the number of living polio people in the United States is 250,000-300,000. With this in mind, the results of several questionnaires conducted in the past three or four years has included less than 1,000 reporting. My plea, therefore, is to emphasize the vast majority of people who are still actively living and are not experiencing any truly new or significantly different findings (not symptoms such as alleged weakness, fatigue, soreness, tenderness, etc.).

In my experience over the past 45 years in treating polio patients and living it in my own life, I have realized several important findings.

Polio people are human beings. As such, and with advancing years, they are subject to the same symptoms and objective findings of abnormality that the usual human being experiences. It is very important, however, not to overreact to X-rays that may reveal a considerable amount of so-called degenerative arthritis of the spine, hips and knees. In my own experience, I have been impressed with the relatively less severe presence of these conditions, even in the involved lower extremities. One cannot interpret subjective complaints of pain, soreness and tenderness by attempting to read the findings of an X-ray.

Of great importance is the maintenance of flexibility and mobility of the body, especially the shoulders, entire spine, and lower extremities. Often polio people, who are limited in amounts of weight-bearing, spend most of the day in a wheelchair and as such tend to slump as they get more tired, compromising the physiology of the heart and lungs and reducing the circulation. The solution is "keep on fidgeting." Particularly in a wheelchair, it is advisable to do a push-up maneuver, elevating the buttocks and trunk at the shoulder level relieving the pressure on the buttocks, straightening the spine and increasing the space for the heart and lungs to function with improved circulation to all these organs in addition to the abdominal organs. The shoulder depressors and triceps elbow extensors are repeatedly exercised whenever this is done.

I am convinced that one can maintain an active, meaningful life. Even seriously deformed extremities can be properly supported by modern techniques available through orthotics and especially-made shoes.

It is my conclusion that polio's long-term history is a continuum from the acute stage to the end, and depending upon the amount of common sense and practical motivation the individual possesses, the rewards will be proportional.