

POLIO NETWORK NEWS

International Polio Network

Fall 1992 ■ Vol. 8, No. 4

Readers Write; Readers Respond

The Spring, 1992 issue of *Polio Network News* (Vol. 8, No. 2) asked the following question: "... a neurosurgeon does not think that the burning in my chest and upper back muscles is due to my polio. He prescribed vigorous muscle exercises. Are other polio people experiencing a burning sensation in muscles?"

Before we share answers from our readers, we would like to explain why we printed the question. We wanted our long-time readers to verify for our new readers that a burning sensation in the muscles is a common problem and that "vigorous exercise" is not the appropriate treatment.

"I had this sensation when I first contracted polio and during stretching exercises following. I now experience a burning pain periodically in my hip and belly muscles. This seems to be tied to over-exertion, but I cannot be sure." Alice E. Sharp, PhD, **Texas**.

"I was diagnosed with post-polio in 1985 and had at that time a burning in my calf muscles, in fact all of my muscles below my knees and above my ankles. It took about a year for the rest to catch up and the burning to leave. Now, I only get the burning when I overdo it, and believe me, that is seldom." Juanita Davis, **Florida**.

"I have experienced this sensation in my upper back, arms, and legs. It seems to occur when I have overdone in some way ... I do have mitrovalve prolapse that seems to cause the burning sensation in the left side of my chest. I hope this information will help. I know I could not solve any problems by vigorous exercise." Lydia Sommers, **Texas**.

"I have the burning in the muscles of my back, shoulders, arms, and my legs from the knees down. Stress and overuse bring it about. Also, lack of use brings on the burning sensation. I was told to do mild stretching exercises. I tried physical therapy and that enhanced the burning sensation." Rose Brotherton, **Ohio**.

"I have had the burning since 1980 and believe me if you do vigorous exercise you will pay with a lot more pain." Jean Nation, **California**.

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Special Feature on Scoliosis, continued

Polio Network News (Vol. 8, No. 2) featured articles by two polio survivors experiencing scoliosis. **Doris S. Benedict**, Deposit, NY, compiled responses from other *Polio Network News* readers, and **Linda Bieniek**, Chicago, IL, wrote about exploring your options when considering scoliosis surgery. The article below provides a professional point of view.

POLIOMYELITIS and SCOLIOSIS

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Scoliosis is an abnormal, side-to-side or lateral, curvature of the spine. It can be caused by 1) congenital structural abnormalities, 2) neuromuscular conditions such as poliomyelitis, spinal cord injury, or cerebral palsy, or 3) without known cause, also called idiopathic scoliosis, which is most often seen in the adolescent population.

Although the lateral curvature is that which is commonly measured, scoliosis produces a rotational deformity as well. This rotational deformity results in the most clinically evident aspect of scoliosis, the rib hump. In addition, the side-view (sagittal plane contour) is also important in assessing the spine. Kyphosis (hunchback) is defined as the forward curvature in this plane; normally the spine has a gentle kyphosis in the thoracic spine or chest region. Lordosis, or backwards curvature, is seen as the swayback aspect of the lumbar spine or low back. Increased or decreased kyphosis or lordosis relative to normal may have effects on spinal alignment, depending upon the person and his/her spines' ability to compensate.

While scoliosis is relatively common in people with neuromuscular conditions such as poliomyelitis, the need for treatment may vary. The prognosis for progression and eventual curve magnitude is related to the age of onset of the curvature, as well as the extent of muscle involvement and muscle imbalance.

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Special Feature on Scoliosis

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In young patients, that is those who have not completed their adolescent growth spurt, bracing is a useful option. Custom-molded braces, including the Milwaukee brace, as well as less cumbersome types such as the Boston brace, or the TLSO (thoracic-lumbosacral orthosis), can be used to prevent or slow progression of curvature in younger patients. For curves of higher magnitude, the amount of force which must be applied can result in chest wall deformity and should be observed for and avoided. In the adult population, bracing is not effective in preventing progression of scoliosis; however, it may be used in certain instances, as will be described below.

Treatment of scoliosis in the poliomyelitis population may be indicated for pain, progression, curve magnitude, or compromise of cardiopulmonary function. The worsening of cardiopulmonary function may be secondary to the magnitude of a thoracic curve or because the collapsing spine prevents adequate breathing. Collapse of a spine can also result in the increasing need for upper extremity support, thereby decreasing mobility of the arms.

Gait and its effect on the spine

There are several unique aspects of the polio patient which make treatment additionally complex. Firstly, distinctive gait patterns are often developed by the polio survivor, depending upon the specific muscle groups and strengths available. Trunk motion may be an important factor in these adaptations, and, therefore, immobilizing part or all of the spine can affect gait. In many patients, stabilizing a

collapsing spine may improve gait mechanics and efficiency. In others, the spine's hypermobility may be used to advantage in gait. However, it may be questioned as to whether this increased motion may accelerate degenerative changes in the spine.

Ambulatory ability may also be affected by muscle deconditioning which can quickly develop in the polio patient after several days of bedrest following surgery. Although most polio patients after spine fusion have unchanged or improved overall function, many need increased ambulatory aids in the early post-operative period, and a few continue to do so.

It may occasionally be useful to brace a surgical candidate pre-operatively, to assess how they might be able to alter their gait patterns. Gait concerns should be balanced with the disability associated with an increasing spinal curvature and associated pulmonary compromise.

Post-polio syndrome

Post-polio syndrome, or the deterioration of muscle strength and stamina long after the initial illness, may lead to impairment of the person's muscle and lung function. Although the presence of post-polio syndrome cannot be correlated with increase risk of progression of scoliosis, increased trunk muscle weakness may contribute to spinal collapse. Pulmonary function tests should be performed if surgery is considered, and may give information as to a person's risk for surgery, and the potential need for post-operative ventilatory assistance.

Degeneration of the spine

Adult scoliosis of the idiopathic type may present with pain secondary to degenerative changes. The

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pain can often be successfully managed with conservative measures, particularly muscle and cardiovascular strengthening programs. Low back pain, for example, is quite common in the adult population, and recovery from such episodes is also usual. This recovery can be facilitated by physical therapy and/or exercise programs which strengthen the abdominal musculature as well as the spine extensors.

Flexibility can be increased where needed by appropriate stretching of tight muscle groups. Strengthening of the arms and legs, as well as aerobic training — walking, swimming, bicycling — are also recommended for idiopathic scoliosis. A physical therapist should help design the exercise program appropriate to the specific symptoms and muscle involvement and should teach and/or supervise the performance of the exercises to ensure that they are done properly and for maximal benefit.

Although this treatment is useful in post-polio scoliosis, one may be limited as to strength gains possible because of the polio involvement. If post-polio syndrome is present, some contend that overexertion should be avoided, although monitored exercise programs do appear to be beneficial.

Because of the complex issues which can be involved in a person with post-polio scoliosis, it can often be helpful if a multidisciplinary approach is applied. An orthopedic surgeon experienced in the care of patients with scoliosis, particularly those with poliomyelitis sequelae, may have pulmonary medicine colleagues evaluate patients and work closely with them in post-operative management. Physical therapists can provide assistance and input regarding gait training, ambulatory aids, and adaptations. Rehabilitation medicine specialists can be of assistance in optimizing the patient's function even if surgery is not indicated.

Indications for spine fusion

Spine fusion may be indicated for progression of curve, curve magnitude, or loss of pulmonary function secondary to these changes. Pain may be a relative indication for surgery if conservative measures fail to reduce it.

Should a person with a paralytic scoliosis secondary to poliomyelitis be indicated for surgery, several approaches may be offered. Early results of spine fusion with older techniques suggest that both anterior and posterior spine fusion were necessary to obtain a solid fusion in many patients with post-polio scoliosis. Halo-traction, either halo-femoral or

halo-pelvic, was applied in many cases to improve the correction obtained with fusion. Today this method is generally recommended only for severe curves with significant cardiopulmonary compromise. In these cases, pre-operative halo-traction may result in improvement of cardiopulmonary function. (A halo is a metal or composite ring which is applied to the patient's head via several pins. Appropriate weights can be attached and countered either by weights attached to the person's pelvis or by their own body weight.)

Posterior fusion, in the back of the spine, was combined with posterior instrumentation and later with anterior instrumentation and fusion. Harrington rods (instrumentation) permitted greater correction, better maintenance of correction, and improved fusion rates than with fusion alone. Harrington rods, until recently the gold standard of posterior spine instrumentation, utilized hooks at either end of a ratcheted rod, across which distraction (lengthening) forces were applied for correction of the curvature. However, rods were less effective if the curve extended to the pelvis, that is, if there was pelvic obliquity.

Sublaminar wires (Luque technique)

The Luque technique, a system of multiple wires attached to rods, was devised to obtain better fixation to the spine. Luque wiring requires the placement of wires at each vertebral level under the lamina, into the spinal canal, and carries an increased risk of neurologic damage. However, damage is uncommon and usually temporary. The application of multiple fixation sites along the spine appears to give stronger fixation and better correction in osteoporotic spine.

The sublaminar wire technique (above) and the variable hook-rod system to be described below can be combined with the Galveston technique for pelvic fixation. This involves placement of the end of a specially-bent rod — the top of which is attached to the rest of the spine via the aforementioned wires — between the sides of the pelvic bone and appears to afford the best pelvic fixation available at this time, as well as the better correction of pelvic obliquity.

Hook-rod systems

Variable hook-rod systems have been recently developed and successfully applied in idiopathic scoliosis. The most well-known is Cotrel-Dubousset instrumentation (CDI). Other systems are the

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Scoliosis (continued from page 3)

Texas-Scottish Rite Hospital (TSRH also known as Danek) and Isola systems. These offer very good correction of the deformity in most cases, and, like the Luque-Galveston technique, often do not require brace or cast wear post-operatively. However, they may not be optimal for some curve patterns, for osteoporotic bone, or where significant pelvic obliquity exists, each of which is common in neuromuscular scoliosis. Because of the relatively fewer numbers of patients with post-polio scoliosis who are requiring spine surgery since the development of the last two techniques, neither of the two has been proven to be "best" for this condition.

Anterior fusion

Anterior fusion may be indicated to improve curve correction or fusion rate. This is performed on the front of the spine, through an incision on the side of the chest and/or abdomen, sometimes accompanied by anterior instrumentation such as Zielke or TSRH. Anterior fusion necessitates the surgical removal of intervertebral disc material in the front of the spine, the placing of bone to facilitate fusion, and the subsequent healing together of the individual vertebrae.

Anterior instrumentation systems require screw placement into the vertebra, their interconnection

RESOURCES

The Scoliosis Association, Inc., P.O. Box 51353, Raleigh, NC, 27609 (919/846-2639) will send "Scoliosis, a Fact Sheet and Home Screening Test," to anyone who sends a business size, self-addressed, stamped envelope. It is also available in Spanish. The Association offers membership to individuals and families for \$12.00 and to corporations, businesses, and institutions for \$30.00. Membership entitles you to receive *Backtalk*, which is published several times each year.

Scoliosis Research Society, 222 S. Prospect Ave., Park Ridge, IL 60068 (708/698-1627). If you call or write, the Society will provide the names of Board Certified orthopedic surgeons specializing in scoliosis in your area.

National Scoliosis Foundation, 72 Mount Auburn St., Watertown, MA 02172 (617/926-0397). The Foundation has prepared packets of information for parents of children with scoliosis, for adults with scoliosis, and for health professionals. In addition to the packets, pamphlets and a newsletter are also available.

with a rod, and the rotation and compression of the entire system to effect correction. Although anterior instrumentation appeared to improve fusion rates and correction, it is often not necessary with the more recent posterior fixation techniques (Luque-Galveston, Cotrel-Dubousset, etc.). However, anterior fusion may still be recommended to improve correction or the likelihood of successful fusion.

A surgeon with experience with scoliosis secondary to poliomyelitis and similar neuromuscular disorders should recommend the technique he or she feels is most appropriate for the particular curve pattern being addressed. The patient should feel free to inquire about and understand the rationale for selecting the recommended technique.

Risks of surgery

Risks of surgery and potential complications are of concern for those contemplating surgical correction and stabilization of their scoliosis. Paralysis and death, the two most devastating complications, are quite rare, unless, for the latter, the person has an extremely compromised cardiopulmonary system. Patients with severe pulmonary involvement may need to be on a respirator for prolonged periods of time. Some experts may recommend a tracheostomy to facilitate pulmonary care and weaning from the respirator, but this is rarely necessary today.

Other possible complications include infection, pseudarthrosis (failure of fusion), instrumentation failure, loss of correction, complications of anesthesia, thromboembolic phenomenon (phlebitis or blood clots traveling to the lungs, the latter of which can be fatal), cardiac and pulmonary complications (including heart attack or pneumonia), need for additional ambulatory aids, and etc. The likelihood of any specific complication occurring in a particular patient, depends of course, upon that patient, including their cardiopulmonary status, curve magnitude, previous surgery, and other underlying medical conditions. These should be discussed on an individual basis with the surgeon.

Conclusion

Spine fusion which is performed to correct or prevent progression of a curved spine, immobilize degenerated segments of the spine, or stabilize a collapsing spine for improvement of function is often successful in poliomyelitis patients. Clearly the goals of surgery should be discussed carefully prior to surgery — it should be understood, for

example, that complete curve correction is not the goal and indeed, not preferable. An arthritic spine may be fused but the aging process affects the entire spine and lesser amounts of pain may be present post-operatively from these sources.

Because of the improvement in surgical techniques and advances in instrumentation, the amount of surgical correction gained and maintained has been markedly improved in the last two decades. More importantly, solid fusion is more commonly achieved with current techniques. Overall, the polio survivor with scoliosis who is determined to need surgery can look forward to a high likelihood of successful surgical treatment.

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Readers Write; Readers Respond

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"I, too, am having this type of burning especially in the midriff area. If I overdue, the burning is almost unbearable. I was on an anti-inflammatory drug and it helped for about a year and a half. My physical therapist recommends exercise, but only five to ten repetitions of each exercise (I do three), two or three times a day. I certainly don't think this person's neurosurgeon has ever dealt with post-polio." Carol Tuttle, Wheeling, **West Virginia**.

Readers respond

Scooter Information

Lois D. Jeavons, Millboro, VA.

"The response to my letter asking about personal experiences with three-wheeled vehicles was overwhelming. What a great, supportive bunch of people we polio survivors are! After practicing denial for 40 years, I now realize what I've been missing. Pretending to be "normal" all these years has been lonely and frustrating. Avoiding reality, I have missed out on a great many positive relationships.

"I am enclosing copies of the letters I received, as well as my analysis of all this information, much of it in great detail and invaluablely helpful. The letters came from many different states, but so far, none from the eastern states and none from my home state of Virginia. Interesting!

"The small Amigo (one battery) was recommended by the majority because of its maneuverability for aisles in a dress shop, for example. It would seem that a van with a lift is the easiest way to go, and of

course, the most expensive. However, one woman said that her husband had built a lift for their van at a cost of \$200 vs. \$1,000. Another said that General Motors paid for their lift when they purchased a new van. She recommended discussing this with a car dealer.

"After investigating four different brands, one woman recommended the Super Scout made by Burke, Inc., in Shawnee Mission, Kansas. It breaks down into four parts each weighing 25 pounds. She uses this vehicle both inside and outside. One woman was disappointed that her vehicle was not suitable for public transportation (the scooter was too long for the bus lift). For outdoor use, one woman prefers the Rascal by Electric Mobility, because it is sturdier than others she tried.

"Everyone cautioned about turning off the motor when getting in or out. It is a scooter and it will scoot! Take inclines at right angles, not head on or you could tip over. Also, everyone agreed that you should read the operating instructions carefully.

"I have come to the conclusion, regardless of what model is chosen, that a lift and a van are essential accompaniments to a three-wheeled vehicle if complete independence is to be achieved. Medicare in Virginia is not willing to pay for any of these additional costs. If they are willing to pay toward a scooter, I would think they should help defray the accompanying expenses.

"In the meantime, I have still not purchased a three-wheeled scooter. Instead, I have purchased a Rolling Walker distributed by NobleMotion Inc. Because I am able to still walk, my doctor did not want me to purchase a mechanized vehicle prematurely. Made in Sweden, the walker is like a miniature shopping cart but has brakes and a seat, so

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Scooter Information

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that I can rest when I become tired. It is very easy to steer and I can fold it up and put it in the car myself. It helps me with my gardening chores, shopping malls, and inside transporting of heavy items, as well as giving me additional support — more so than my cane. I am thrilled with it.

“Thank you one and all for sharing your experiences with me. What a wonderful outreaching service this newsletter performs. Thanks again.”

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Additional Resource:

For a copy of AARP product report on walkers, send a postcard to: AARP, Fulfillment, 601 E Street, NW, Washington, DC 20049. Ask for Stock No. D 14390.

Readers respond

What's Happening with Research Medications

Roberta Simon, R.N., Darien, IL

When I asked the *Polio Network News* to request that you share results you have had with research prescriptions being tried for treatment on the late effects of polio, I expected to hear from many of you regarding the drug Mestinon or pyridostigmine. Much to my surprise that was not used by many people. My other surprise was that drugs being tried seem to be regional in origin. I knew Mestinon was first tried at the University of Chicago and its use appears to be most accepted by people being treated by physicians who are in the midwest or were here in the '80s and have since relocated. Another part of the country, chiefly the west coast, appears to be extensively using Eldepryl.

MESTINON was first prescribed by research neurologists from two large universities in the Chicago area. It was designed for use in myasthenia gravis, a neurological disorder which causes weakness that involves most frequently the cranial and eye muscles. The limbs (extremities), respiratory, and swallowing muscles may also be involved. However, no pain or muscle twitching is present in people with this disorder. Of course, as with any other neurological disorder, the symptoms may be mild or severe enough to be life threatening. The treatment is with large doses of Mestinon, three to nine tablets (180 to 540 mg.) three times each day.

In treating post-polio problems, only 90 to 180 mg. are taken each day. Some individuals with extreme fatigue related to post-polio syndrome (PPS) may be taking more, but this is unusual and not the rule. Mestinon increases neurotransmission across the neuromuscular junction, thereby improving strength. Caution is usually advised when this medication is prescribed. Although some report dramatic improvement of their fatigue, others report mild to serious side effects. The other problem with this medication is that some individuals feel so well that they have difficulty not overusing their muscles.

Some of the side effects experienced with Mestinon are increased mucous which increases salivation and nasal mucous. Increased mucous in the intestinal tract may cause diarrhea or intestinal cramping. Twitching of the skeletal muscles (fasciculations) or

cramping may also be a side effect. One individual reported respiratory difficulty following the use of 1/2 tablet of this medication and had to be placed in intensive care for a period of time on ventilation assistance. One individual wrote, "this is certainly not a drug to be played with." This person reported that the secretions caused face swelling and sinus congestion which led to difficulty in breathing due to sinus and nasal congestion. Another was given 180 mg. in a timed release tablet all at once and reported severe abdominal cramping which could not be controlled even with a lesser dose. Eventually, this same individual developed difficulty with the parotid gland which was believed to be caused by the increased mucous. (The parotid gland is located near the ear and is a salivary gland.)

Several persons reported good to excellent response from Mestinon without difficulty or side effects. Relief of fatigue and improvement of weakness was reported with an improvement in ability to do activities of daily living. One individual has taken this medication for an eight-year period without significant consequence other than improvement of ability to function with improvement of endurance, fatigue, and strength.

PREDNISON use was reported by a few people but was used primarily to treat health difficulties other than PPS such as asthma, poison ivy, and allergic reactions. All reported improvement in the difficulty being treated, but side effects were also reported by all but one individual. The one person reporting good results stated decreased fatigue, weakness, and increased muscle strength. This person requested long-term treatment but was denied by her physician because of the serious long-term effects and side effects. Another individual reported that PPS symptoms improved while on this therapy, but after discontinuing the drug, function was decreased for a period of one to two weeks. Prednisone is a steroid and should be used with caution because its long-term effects may be quite serious. The National Institute of Neurological Disorders and Stroke (NINDS) is conducting a study using Prednisone in small doses, but I did not hear from anyone involved in this study to know what good or bad experiences they are having.

BVITAMINS have also been widely discussed. A physician from the Netherlands told me that B vitamins are widely prescribed in that area for the control of neurological symptoms. Vitamin B 6 (Pyridoxine) is reported to have relieved joint pain and the generalized aching and pain which was

being experienced by one person. This vitamin is available in meats, cereals, lentils, nuts, bananas, avocados, and potatoes. A deficiency may cause symptoms in adults of peripheral neuropathy (numbness or decreased sensation in the arms or legs) and memory difficulties. One type of anemia may also be related to a Vitamin B 6 deficiency. Pyridoxine is a constituent of an enzyme concerned with the metabolism of amino acids, the building blocks of protein. Vitamin B deficiency is rare if a healthy diet is eaten each day. Many physicians who treat post-polio difficulties suggest that their patients take a multiple vitamin and eat a well-balanced diet each day. For most of us, that is adequate.

ANALGESICS (pain medication) are being taken on a regular basis by three individuals who responded. This is not advised. Dr. Jacquelin Perry explains this. Pain is your body's way of telling you that something is wrong. In PPS, pain is a symptom that is experienced when your activities are excessive and should be re-evaluated. Your body may be telling you to find a way to rest more frequently, to conserve energy, or perhaps even discontinue some activities. Often a brace will assist in eliminating pain. Contrary to what some believe, analgesics are addictive.

Since PPS is a slowly progressive health difficulty, it is much wiser to modify your lifestyle to eliminate the pain than to medicate yourself. Short-term use is acceptable when suggested by your physician, as long as the medication prescribed does not have muscle relaxant qualities. These drugs may actually exacerbate your symptoms and, with respiratory muscle weakness, may even cause an emergency situation which may be life threatening.

Various non-steroidal, anti-inflammatory drugs (NSAIDS) are being used for control of pain. These include Motrin, Advil, Naprosyn, Volteran, etc. Gastrointestinal symptoms are the most frequent side effect from all of these drugs, and most should only be taken with food. Fluid retention may also be a problem, as well as kidney difficulties. These drugs should not be taken lightly as they may cause serious side effects and should be monitored carefully by your physician.

ELDEPRYL, as I previously stated, is a medication that is being used frequently in the western states. Another name for this drug is Deprenyl. The generic name is selegiline hydrochloride and was

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Research Medications

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designed to be used for Parkinson's disease in conjunction with levodopa.

There are many adverse effects to Eldepryl that are possible, including some neurological symptoms, so it is essential that a physician carefully monitor your progress while you are on this medication. The dosage prescribed for PPS is less than the recommended dose used with Parkinson's disease.

One person reported a decrease of muscle pain after a year of treatment, but states no increase in energy was noted. Another individual stated no improvement and discontinued the drug after a few weeks because of gastrointestinal difficulties. A third individual reported increased strength with a reduction in pain after using this medication for six months. The medication was then discontinued for three months and when a decline in function occurred, it was resumed, and the person is now experiencing a reduction in pain and increased strength.

A double blind study with this drug is being planned by a physician in the west. A double blind study is when half the participants are given the drug and half a plain tablet without medication with the participants not knowing which they are taking. Careful records and follow up are done to determine the effects on each group. All drugs are tried for efficacy this way by the Food and Drug Administration before being released to the public for a particular use. This drug is approved only for the treatment of Parkinson's disease, just as Mestison is only approved for use in myasthenia gravis. Both drugs are considered research medications in the treatment of PPS.

AMANTADINE (**Symmetrel**) is another medication that has been tried for control of PPS symptoms. This drug was designed to be used for Parkinson's disease and was later found to be effective in the relief of symptoms and for prevention of influenza A virus infections of the respiratory tract. In two controlled studies, it has been shown to improve the fatigue of multiple sclerosis. One physician on the east coast reported studying nine patients who were taking symmetrel. Eight reported improvement of fatigue, and seven expressed a desire to stay on the drug. It was reported that some experienced a dramatic improvement in fatigue, while others only a slight improvement. One person went off the medication for a period of

time and when therapy was re-introduced is reported to have again noted a decrease in fatigue. This medication also has been tried in the midwest with one person reporting a decrease in fatigue and muscle twitching (fasciculations). Others noted no change in symptoms. The physician who reported this information is also suggesting a double blind study.

ACETYL-L-CARNITINE (an amino acid) is a medication that is being reported by individuals in Germany, Italy, and Switzerland for treatment of PPS. A physician from Switzerland reported that his patients reported increased strength, endurance, and less fatigue, enabling them to manage their daily work and free time with less difficulty. Some even reported less pain. He states that only a few individuals reported no effect from the medication.

Acetyl-L-carnitine is reported to have the ability to stimulate nerve cells to produce proteins, new cell membrane, and release acetylcholine. It is a prescription drug in Europe and is marketed in the United States by health food stores in a different form as a nutritional supplement to increase muscle strength. It should be noted that the U.S. drug lacks the acetyl component necessary for effective treatment. FDA approval may be sought after additional data is collected by the pharmaceutical company investigating this drug. If the drug is marketed, it will contain the acetyl component. A study done in Italy with this drug showed maximal exercise intensity could be increased with this medication, but this study was done on healthy individuals without neuromuscular disease.

L-CARNITINE is stated to play an important role in the lipid-related energy production which is important in muscles used for short duration at high intensity exercise, but not with long duration, low intensity exercise. An increase in L-carnitine is believed to increase reinnervation of muscle fibers and a decrease is found in severe neurogenic atrophy.

It certainly will be interesting to hear more about this drug in the future. Perhaps this is another drug that would benefit from a double blind study. In discussing its use with the health food store owner close to me, I was told that individuals who are trying to increase their strength for weight lifting and marathon running are very interested in this drug.

THEOPHYLLINE is another medication that has been prescribed for a few individuals with respiratory muscle weakness. In some research studies it has been found to strengthen the diaphragm and may allow one to go without ventilation assistance for a period of time and relieve pain in the rib cage area from muscle fatigue of respiratory muscles. Not all pulmonologists subscribe to this treatment, but others feel it is extremely helpful. Although I usually do not mention what I myself have done, I do want to state that I took this drug for five years with excellent results prior to being put on ventilation assistance at night two years ago. I continue to take it at the present time. Prior to using theophylline, I felt like an elephant was sitting on my chest constantly! Believe me, I was thrilled when he went back to the circus!!

Last, but certainly not least, was a letter I received from a person with PPS who has taken gamma globulin for five weeks with Ergamisol and reports no change in symptoms. Ergamisol boosts the immune system and is usually used as an adjunct to chemotherapy for cancer patients. A trial of Interferon was planned for this patient in the future.

As you can see, a great variety of medications are being tried for relief of post-polio symptoms, but none has been tested with a double blind study and none has been proven to be effective. For every person who reported relief from a medication, I heard from someone else about an adverse reaction or effect or no change at all in their symptoms. The only way we can sensibly make an informed deci-

sion about any of these medications is to learn as much as we can about their actions, reactions, and possible side effects. We should ask about both the long and short-term problems that may occur. The public library has a vast amount of literature on medications, and often your local pharmacist would be willing to discuss these issues with you.

I myself have taken one of these medications for an eight year period without complication and with good results, but I know others who have tried the same medication with many difficulties and complications. You are the only person who can decide what is right for you, and what risks you are willing to take.

I do hope that the National Institutes of Health (NIH) will approve some money for polio research this year making it possible for more researchers to do studies on some of these medications and perhaps draw some conclusions on their efficiency for the population of persons affected by the late effects of polio.

Special thanks to ...

Burk Jubelt, M.D., SUNY Health Science Center, Department of Neurology, Syracuse, NY.

Post-Polio Research

We do not, as yet, have specific information to report on the effort to ask congress to attach a dollar amount onto the request for post-polio research at NIH. Individuals on the National Polio Research Coalition list will receive information as soon as it is available, and we will report to our readers in the next issue.

A Friend Remembered ...

In 1923, when she was two, Hope Thomson contracted polio which affected her arms, legs, and throat. After years of therapy and surgery she recovered almost completely and established the first professional department of social work at Temple University Hospital in Philadelphia.

During an interview in 1990 on National Public Radio, she related her polio experience and recalled her dread of walking down the long hallway at Temple. She equally disliked waiting for the elevator. The problem of standing or walking indicated to her something was wrong with her legs.

Over the years she went "from doctor to doctor, being told that nothing was wrong." The last thing she expected in retirement was not to be active. "I was going to be such a political activist, pushing for

reforms in social work. Now I am in bed more and more hours a day, hire an attendant part-time, and use creative assistive devices. You become determined that you can't afford attendants all of the time and determined that you are going to be independent."

Hope Thomson died March 27, 1991, and was remembered at a service in appreciation of her life as a woman of integrity, courage, warmth, humor, and compassion.

International Polio Network is grateful to Hope for remembering the organization in her will. Her contribution will assist us in fulfilling our mission - supporting the independent living, self-direction, dignity, and personal achievement of people with disabilities everywhere.

SURVEY RESULTS

The article, *U.S. Post-Polio Clinic Results (Polio Network News, Vol 8, No. 3)*, generated several comments and questions. We are pleased that so many of you thoughtfully, actively, and positively participate in our Network and are pleased to share comments.

Thanks were received from support groups working with local health professionals to establish a new clinic; health professionals considering a new clinic; survivors who have not had a baseline evaluation, but now have an idea of what to expect when visiting a clinic; clinics who felt their current clinic was right on target by comparison; and from clinics who were contemplating changes.

Do medical residents see patients?

Some viewed a "yes" as a positive because these clinics are producing new physicians knowledgeable about the late effects of polio. Others were frustrated to think that they would go to a clinic expecting to see the well-known physician in charge and would end up being seen by a resident.

Do you have a Cybex to evaluate muscle strength?

Many clinics responded, "Yes, but do not use." Reasons why clinics do not use the Cybex include: instrument testing is usually done in research settings and is time consuming because of the exact positioning required; instrument testing involves limited numbers of muscle groups and gains information to be used in a specific manner, whereas clinics require that a greater number of muscles be tested. Most clinicians are looking for a functional assessment, i.e., how does this patient's weakness affect his/her ability to function. And, lastly, only manual muscle testing can detect

muscle substitution which is particularly important in post-polio individuals.

Cost.

Our original questionnaire did ask the approximate cost of the initial visit but promised not to publish the amount for various reasons — costs change and the total cost is so dependent on number and type of specialists seen, and therefore, can only be calculated after the evaluation.

However, a few comments can be made. The initial evaluation ranged from \$120 to \$1,200 with the average being \$325. Some clinics only see individuals by referral (a question we neglected to ask), so a patient brings previously done test results with him/her. Many physicians stressed that clinics are not intended to replace a primary care physician and expressed the need to coordinate with them.

Below find additions and corrections to the survey published in Summer *Polio Network News*, Vol. 8, No. 3.

What medical professionals are physically present to see patients at the time of their first evaluation as well as return visits?

Clinic I.D. #	Physiatrist	Neurologist	Orthopedist	Pulmonologist	Physical Therapist	Occupat. Therapist	Recreat. Therapist	Respira. Therapist	Speech Therapist	Social Worker	Psychiatrist	Psychologist	Orthotist	Nutritionist	Other (Pls. name)
CORRECTIONS															
6		C	C	C	●			C	C			C	C		Family Physician
29	●	C	C	C	●	●									
30	●	C	C	C	●	●	C	C	●	C	C	●	C	C	Exer. Physiol., Seat. specialist. Voc. therapist
47	●	C	C	C	●	●	PRN	PRN	PRN	●	C	●	PRN	PRN	Rehab Nurse
ADDITIONS															
61	●	●	●	●	●	●	●	●	●	●	●	●	●		
62	●	●	●	●	●	●			●		●		●		

KEY: ● = Available at time of first visit F = Available at following visit C = Available by consult PRN = As needed

Clinic I.D. No.	Do you have a Cybex to evaluate muscle strength?	Is a brace mold made at time of visit or must patient return?	Approx. Date Clinic Opened
CORRECTIONS			
6	NO	If necessary	1985
29	If needed	Return	1992
30	YES	Return	1990
47	YES	NO, referred to orthotist	1991
ADDITIONS			
61	YES	YES, as appropriate	—
62	YES	YES	May, 1991

Clinic I.D. No.	Do medical residents see patients?	CBC	Blood Chemistry	Electro-myogram	X-Rays	MRI	CT Scans	Others (Please Name)
CORRECTIONS								
6	Occasionally							Pulmonary function
29	NO	●						Pulmonary function, EMG, etc., if needed
30	NO	●	●	PRN	PRN	PRN	PRN	Cortisol, ACTH, Thyroid
47	Occasionally							None routine, all individualized
ADDITIONS								
61	YES							None routine, when appropriate
62	NO	●		●	●	●		Some for surgical cases only

Clinic No. **Clinic Name and City, State**
6 Mercy Medical Center, Denver, CO
29 Thoms Rehab Hospital, Asheville, NC
30 Kessler Institute, East Orange, NJ
47 Stewart Rehab/McKay Dee Hospital, Ogden, UT

Clinic No. **Clinic Name and City, State**
61 William Beaumont Hospital, Royal Oak, MI
62 Albert Einstein Medical Center, Philadelphia, PA

International Polio Network publishes a **Post-Polio Directory** which list clinics, health professionals, and support groups around the world. The cost is \$3.00 which includes postage. If you want only the additions and corrections to the last directory printed in February, 1992, please send a business sized, postage paid envelope to: **International Polio Network, 5100 Oakland Ave., #206, St. Louis, MO 63110 USA.**

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Exceptions to obtaining written permission to reprint include those areas of the Calendar, Resources, Potpourri, and Post-Polio Bibliography.

International Polio Network has available its pamphlet "The Late Effects of Polio — An Overview." The pamphlet, written as a synopsis, serves to inform those experiencing the late effects of polio, and those who are not knowledgeable about the late effects of polio.

The pamphlet is free (with a self-addressed, 52¢ stamped business envelope) up to five copies. Six-25 copies cost \$3.00; 26-50 copies cost \$6.00; 51-75 cost \$9.00, and 76-100 copies cost \$12.00 — all postage paid.

The pamphlet has also been translated into German.

To order, write or call International Polio Network, 5100 Oakland Ave., #206, St. Louis, MO 63110 (314/534-0475).

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The month your subscription is due is above your name on the label. ♦ Renewal notices are sent to serve as a reminder.

Potpourri

HEALTH PROMOTION PROGRAM MANUAL

Stay Well! A manual for a health promotion program edited by Sunny Roller, M.A., and Frederick M. Maynard, M.D., available from Polio Network, Inc. (Michigan), has received positive comments, especially for its thoroughness and usability.

It presents three important strategies for staying well: Sound Nutrition, Individualized Exercise, and Lifestyle Enhancement Techniques (including stress management).

Recognizing that the cost of \$35 may prohibit purchase without knowing more about its content, International Polio Network, with Michigan's permission, will mail a photocopy of the table of contents to anyone sending an SASE to us. Complete copies at \$35 each (postage included), may be ordered direct from Polio Network, Inc., 2877 S. Ennis, Ithaca, MI 48847 USA. Allow six weeks for delivery.

PUBLICATIONS

Through The Storm, by Robert F. Hall, has been reduced in price (\$6.00, US; \$7.00, overseas).

Through the Storm describes Bob's polio experience and that of his rehab buddies Spook, Suede, Russian, Onion, Putzie, and their physical therapist Zim. Send check or money order to Robert F. Hall, 15815 Gleason Lake Dr., Plymouth, MN 55447 USA.

POST-POLIO BIBLIOGRAPHY

"Correlation of Creatine Kinase and Gait Measurement in the Postpolio Population." W. P. Waring and T. M. McLaurin. **Archives of Physical Medicine and Rehabilitation** (1992), Vol. 73, pp. 37-39.

Measurements of stride length, gait speed, and distance walked during seven days were obtained from 15 post-polio and eight control subjects. There was a significantly positive correlation between CK levels and the distance walked during the previous 24 hours.

The findings of this study illustrate the impact of gait abnormalities on the ambulatory abilities of the post-polio population. The correlation of CK with ambulation supports the association of exercise as a source of elevated CK levels in the post-polio population.

"A pilot program of nutrition education and exercise for polio survivors: A community-based model for secondary disability prevention." Carolyn J. Hoffman, MS, RD, and Frederick M. Maynard, MD. **Topics in Clinical Nutrition**; September, 1992; Vol. 7, No. 4, pp. 69-80.

This article describes a pilot program of nutrition education and exercise that was designed to meet the needs of individuals experiencing the late effects of polio.

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CALENDAR

If you are planning a conference, please supply information to **Polio Network News** for inclusion in the Calendar as soon as details are known. Recent events have not been listed because the information was not received before printing deadlines. Yearly deadline dates for our quarterly publication are: January 15, April 15, July 15, and October 15.

Meeting The Challenges of Aging with a Disability: Lessons Learned from Polio and Stroke, Long Beach, CA, March 19-20, 1993.

Information will be presented on medical, physical, and psycho-social consequences of aging with polio and stroke; understanding the secondary complications that occur as people age, risk factors associated with these complications, appropriate treatments and the roles of family and support groups. Contact: Mary Marquez-Ackerman, Rehabilitation Research and Training Center on Aging at Rancho Los Amigos Medical Center, 7600 Conseulo St., Downey, CA 90242 (310/940-7402).