

POLIO NETWORK NEWS

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CDC Study Completed

Frederick M. Maynard, M.D. and a team of investigators from the University of Michigan Medical Center, Ann Arbor, Michigan, have completed their final report for the study *The Late Effects of Polio: A Model for the Identification and Assessment of Preventable Secondary Disabilities*. A summary follows:

OVERVIEW OF THE STUDY

The major goal of this study was to develop methods for identifying and investigating preventable secondary disabilities among people who have already had a primary disability for many years. Project researchers studied 120 people with varied levels of disability caused by polio. Each person completed a 54-page Home Survey before coming to the University of Michigan Hospital for a five-hour series of medical examinations and tests. The information that was collected was then computerized and analyzed by project researchers. This entire study took 2-1/2 years to complete.

RESULTS OF THE STUDY

Data analysis led to three categories of findings.

First, the overall group of study participants was described. The persons in this study were predominantly married, well-educated, and working, with a few in a low economic group. Eighty-two percent had a treatable musculoskeletal problem of some kind. Seventy-nine percent had weakened lower limbs. Seventy-seven percent had nerve problems of the hand or wrist. Thirty-five percent of the group were obese and 31% had another disease that further complicates their health status. Fifteen percent were depressed (which is lower than the national average). The rate of other secondary conditions were as follows:

CONDITION FREQUENCY

| | |
|---------------------------------|-----|
| Hand/Wrist Arthritis | 48% |
| Treatable Upper Limb Pain | 55% |
| Treatable Spinal Pain | 46% |
| Treatable Lower Limb Pain | 50% |
| Treatable Walking Problem | 68% |
| Stair Climbing Problem | 55% |
| Hypertension | 8% |
| Clinical Anxiety | 19% |

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“Suggestions for Exercise”

from Fifth International Polio & Independent Living Conference in Saint Louis

Polio survivor, **Nancy Caverly**, St. Louis, MO, introduced the topic of exercise and energy conservation by sharing her experiences. **Jacquelin Perry, M.D.**, Chief, Pathokinesiology/Polio Service, Rancho Los Amigos Medical Center, Downey, CA, and **Richard Owen, M.D.**, Medical Director, Sister Kenny Institute, Minneapolis, MN, then offered their thoughts and suggestions about exercise.

NANCY CAVERLY: About 15 years ago, with my youngest child securely placed in school, I decided to become a jock and take part in one of the major exercise programs in St. Louis. The first day of the class, I was impressed by my size, which was larger than all of the thin women who had signed up to become super-jocks. Also, I was impressed by my inability to perform most of the exercises. Nevertheless, on my little pad on the floor, I pursued all of the exercises I could possibly do. I went home after an hour of a rigorous workout, took a hot bath, and went to bed for the rest of the day. I did finish the six-week course, because I had paid for it, but after the first day I did only the exercises that my body would allow me to do comfortably and without strain. I chalked the experience up as one major mistake in my personal quest for how best to maintain my body for the years to come — this was not the way.

The other exercise I tried doing, because I had done it extensively before polio at age 17, was swimming. My first morning included walking down a long flight of steps, changing clothes and getting into the pool, and swimming with businessmen who came to do 50 laps on their lunch hour. That day, I did 36 laps, or 1/2 mile, and again went to bed for the day. This time I did not wipe swimming off of my list of acceptable exercises, because I knew that swimming had many positive points for exercising. I decided to start low and build up my laps to find out the reasonable number for my body. Now, I swim two days a week, between eight and ten o'clock in the morning. The reasonable number for me is 20 laps in the 100% accessible 25 meter pool at a local school. I do ten laps

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of freestyle or crawl stroke, two laps of back stroke, two laps of elementary back stroke, two laps of breast stroke, two laps of side stroke, and a few stretching exercises. For the last two laps, I do whatever makes me feel the best. I check my pulse rate after about ten laps and it usually is about 112 to 118 a minute, the minimum necessary for cardio-vascular conditioning. It takes me approximately 20 to 25 minutes to do that number of laps. The cardio-vascular stimulation that I am getting from swimming is great; I am unable to exercise in any other way (walking, cycling, etc.) for that length of time.

On the Tuesdays and Thursdays after swimming, my energy level during the day is much higher. I do not go to sleep at eight o'clock watching a movie on television. I am still moving at ten o'clock that night, not with energy that I should not have, but with energy that is available to be used.

After swimming for five years, I was telling our local pharmacist that I was having some low-back pain from an old diving injury. He suggested I try swimming with fins. With fins, I get faster movement so that it takes me less time and fewer strokes, but I get more resistance. The low back pain decreased within a three-month period and has not recurred. As a polio survivor, I know I am going to find a year-round swimming pool where I can swim at least two times a week, wherever I live in the future. That is where my body and I are with exercise. What we would like our professional staff to discuss is what exercise they feel may be appropriate for you.

DR. PERRY: Today I am going to focus on two aspects of exercise and energy conservation — life-

style modification and use of orthoses.

There are two kinds of exercise — aerobic and strengthening. Aerobic exercise is using the leg or arm muscles to make demands on the heart and lungs. This means that in order to do aerobics one has to have extremity muscles. Some people have strong legs and poor arms, so they walk or ride a bicycle. Some people have strong arms and poor legs so they swim.

The calf muscles are the hardest working muscles in walking, and they commonly wear out. Individuals with weak calf muscles should not walk or run, but bicycling is a possibility. I recommend that people use stationary bicycles unless they live in a community with nice level paths and not too many cars. On the other hand, one is using the thigh and knees during this type of exercise, and so it may or may not be useful. One can plan an aerobic program if one has muscles that will tolerate a 20-minute activity at a moderate pace without getting sore, fatigued, or losing strength. As Dr. Owen's group has described at Sister Kenny in Minneapolis, an interrupted aerobic program also can be effective. Each exercise interval of two-three minutes is followed with one minute of rest. This enables the post-polio survivor to get more exercise without overdoing.

The nice thing about water exercise is that anything from "puttery paddling" to real swimming is available. Again, one has to remember that swimming uses the shoulders and arms. Before pursuing a program, be sure they will take that kind of strain. The purpose of aerobics is to train the heart and lungs because they are the source of energy.

In general, activities below 50% of maximum capacity are non-fatiguing; above that level, individuals huff and puff. The goal of exercise is to keep the effort above what we do every day with some periods of

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activity, or otherwise we will continue to huff and puff. I live with an individual with severe arthritis. There is nothing to exercise, and so she huffs and puffs when she gets dressed. Every time she gets checked, her heart is just fine. Her aerobic exercise is the task of getting dressed.

The other type of exercise is strengthening exercise which is indicated for muscles which are not at their maximum capacity. Strengthening exercises are short duration, high-intensity activities focusing on the muscle tissue to improve its physiology. At Rancho Los Amigos, we use an intensity of about 60 or 70% of a single repetition maximum and have patients do five repetitions. When that gets easy, we increase the repetitions to ten, and later we increase the resistance.

Polio survivors have three major complaints: pain, weakness, or fatigue. There is no examination that can tell whether fatigue and weakness are due to underuse or overuse. Therefore, I try a period of exercise.

On the other hand, I consider muscle pain a sign of injury and overuse and will not give exercise in the face of any pain. In that instance, we modify the life-style to a pain free system, and then we can try some exercise. When we try exercise, we give three rules: if the exercise makes you feel better, continue it; if the exercise makes you feel worse, cut it in half; and if the exercise still makes you feel worse, stop because it is now doing damage.

If a person has enough strength to take some resistance, which means they are a Grade 3+ or 4+ or better, we work on the major muscle groups. (Weaker than that means there is not enough muscle mass to really respond because 3+ is about a 20 to 25% muscle.) If the person has enough strength, we exercise the quadriceps, the hip abductors, the hip extensors, the knees, and the calf muscles. We do it bilaterally and unilaterally.

We evaluate where the weakness is and make our exercise plan accordingly. In general, I have not found underuse of the arms as often as I have found some response to exercise of the lower extremities. The shoulders are hard not to use, and they tend to get overused in the polio population.

What has been our experience with this kind of exercise? We have found that it is not terribly effective, but one could say we did not do enough. Forty percent of the patients are better (more endurance or a strength gain of 1/2 grade), 30% of them experienced no change, and another 30% were worse. They could not tolerate the exercise, and their life-style was using their muscles to the maximum. When people have joint pain, exercise has not been very helpful. To those with strained ligaments and joints, it made essentially

no difference, and we have gone to other devices.

A weak calf is the most common problem because it is a muscle that is used all of the time. A tightness to five degrees forward of the vertical is a very useful way of substituting for a poor calf. Having a calf that will not come up to neutral the body weight or twists the foot is not good, but having a calf that is overly weak is also not good. We do not over-stretch the calf. The point is that there is selective tightness as well as selective weakness.

The penalty of the weak calf, and the reason it is always overlooked, is that in order to keep the body upright, one flexes the knee and the strain is on the quadriceps. People commonly complain of either a painful calf or a painful quadriceps, or both, and so we, at that point, provide stability of the knee. Some people solve the problem by loading with the foot down, so they have flat foot contact and no stimulus for knee flexion. If a calf had a contracture that came to five degrees of neutral, it would be solved that way.

The most common form of orthoses today for a weak calf is a plastic shell. Some are good and some are bad. The depth of the cut determines their flexibility. The big problem with a solid plastic shell is that it prevents the foot from dropping down at all. If it is cut way back (3/4 inch wide), it can be used just to pick up the foot for drop foot and that allows the foot to come down. However, if one has a thick or dense shell, when you load with a heel strike, it will drive the foot down causing increased knee flexion and increased strain on the thigh. So, if a person has normal quadriceps or can balance on the heel until the whole body rolls forward, it is not a problem. But if one has a sensitive quadriceps, it can be overloaded by this kind of shell. To correct that, a hinged plastic orthosis has been designed with a variety of stops. Some have a plastic strap that catches on a screw. We happen to use a flexible strap because it buckles and more readily allows the foot to go into free plantar flexion for easy loading. For better knee control we also have a light plastic shell molded to the thigh. When the back-knee posture used for standing stability becomes excessive and painful, an off-set knee joint can limit the knee position and still allow the knee to be free. If the patient lacks knee stability because there is both quadriceps weakness and flexion deformity, the joint has to be locked.

If the polio came in adulthood and the legs are equal length, we add a lift to the other leg to help toe clearance by the braced leg. Effective bracing has been very good for both the people who have overuse in the muscles, and the people who have strain in their ligaments and joints. Bracing has not made any of the

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joints worse. Once in a while with bracing, we have a little trouble getting balance among the different muscles and have had a few of our “muscle” people who do not like them, but in general, it has been a very successful program.

DR. OWEN: Last night I went to bed feeling rather comfortable about my preparation for today, and then at about three in the morning, I woke up with an odd feeling that I had not *listened to my body*. The admonition from some of the scientists talking to us yesterday was that we polio survivors should listen to our bodies. I then had an interesting thought. I tried to listen to my body, but we were not talking the same language!

Why do I bring this up? It is part of the caution that I would like to offer with regard to exercise and fatigue. We have been trained from the early days of the management of our polio to ignore what our body tells us. We ignore the fact that we are walking with very weak groups of muscles and ignore pain. We were taught by our physical therapist and by our parents that we were just as good as any of the other kids on the block, and that taught us to ignore the normal messages intended to warn us that we have gone one step too far.

Listen to our bodies. That is exactly what Nancy did with her exercise program. She exercised, experienced weakness, and had to rest all day. So, she modified her program. She swam many laps, recognized that she was overdoing, and modified her program once again.

Modification is one of the keys to an exercise program. In our exercise program at Sister Kenny in Minneapolis, Minnesota, we emphasize cardiopulmonary conditioning. We recommend an interval training technique of exercise. Our conditioning program suggests 20 minutes a day, three times a week. The result is as successful cardiopulmonary conditioning as a non-disabled individual doing a similar exercise.

Individuals exercise for two to three minutes building up the heart rate and then rest one or two minutes and then exercise again. (Nowadays runners use this technique to train for short distance runs.) Exercises have to be done with a chance to breathe in between, and aerobic exercise gives the muscles a chance to rebuild their oxygen supply between contractions. One of the objections I have to apparatus exercise is that enthusiasm to do a great job (and impress everybody) has people doing the whole program without one breath, and that is pretty silly.

Dr. Jacquelin Perry and Sister Elizabeth Kenny are on a similar track as far as the treatment of polio. They both believe that one should not exercise a painful muscle. They advise not to do exercise in the presence of pain, and not to do exercise that then causes pain.

I agree with these cautionary notes and would add — listen to your body. But, the challenge may be to find out what language your body is using.

Intentional exercise should be thought out, should be individualized, and should be cautiously done. That is why so many professionals at this conference dodge the major questions about what you should do for yourself. An exercise program should be individualized and should fit the rest of your life-style. If you are involved in very rigorous activity at work, an intentional exercise program may be time consuming, boring, and too much.

Another caution is that tight muscles should be stretched before exercising. The reason is partly to prevent pain and partly to prevent injury. Muscle strengthening should be goal-oriented and set in a framework of general health status. There are muscles that are important to strengthen from a postural standpoint. Abdominal muscles and some of the hip muscles can be strengthened after prolonged inactivity.

Many times people ask about losing a muscle in the leg if it is braced. There is an advantage to bracing the weakened muscles below the knee because the over-use effect there of walking is so great. (I have one leg braced and the other one not. It is partly habit and partly the fact that I still use my right foot for the gas pedal.) I think that some of the functional aspects of living determines whether or not we use a brace even in the face of good advice from experts.

Last week, I evaluated a man who walks in a most exaggerated hyperextended fashion. Muscle tests reveal he has nothing to walk with, but he refuses to use or wear a brace. He does not want to look “crippled.” If there is a way to get someplace faster, with less energy consumption, and at the same time enjoying it more, then we ought to take advantage of the fact even though we think we look “handicapped.”

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Non-Fatiguing General Conditioning Exercise Program (The 20% Rule)

Stanley K. Yarnell, M.D., Department of Physical Medicine and Rehabilitation; Jill Sweringen and Lizanne Pastore, Supervising Physical Therapists, Post-Polio Clinic, St. Mary's Hospital and Medical Center, San Francisco, California

Since 1981, 711 patients have been seen in the Bay Area Post-Polio Clinics. The most frequently complained of symptom was unaccustomed fatigue (79%). The causes of fatigue may be multifactorial, but it has been our observation that a significant number of polio survivors complaining of fatigue (close to one-third) can date the onset of their profound fatigue to the period after illness, surgery, or trauma, suggesting that deconditioning of the muscle fibers of the delicate old polio motor units is a significant contributing variable. Furthermore, we have noted that polio survivors generally take three to four times longer to convalesce from surgery, illness, or trauma than individuals who have a full complement of anterior horn cells. The non-fatiguing general conditioning exercise program using the 20% rule was designed to help restore stamina or endurance for those individuals who have continued to be bothered by profound fatigue following surgery, illness, or trauma.

The program begins by determining the polio survivor's maximum exercise capability with the help of the clinic physical therapist. The type of exercise can be in a pool or on dry land using an arm ergometer or an exercise bicycle, depending on the individual's abilities and preferences. If the individual prefers swimming, the maximum number of laps that the patient can swim is used as the maximum exercise capability. If the survivor has considerable residual weakness and is only able to swim one lap in half an hour, then the amount of time actively swimming can be used as the maximum exercise capability rather than the number of laps.

Having established the maximum exercise capability, the polio survivor is instructed to begin his aerobic swimming program at 20% of the determined maximum exercise capability. He can swim three to four times per week at that level for one month, and then he is instructed to increase by 10%. For example, if an individual is able to actively swim in a pool for half an hour, then one-half hour would be his maximum exercise capability. He would begin swimming just six minutes per session three to four times per week for a month before increasing the amount of time actively swimming to nine minutes three to four times per week for another month. Then he would increase by 10% once again so that he was actively swimming 12

minutes per session three to four times per week for another month, and so on. After three to four months our patients have reported that they feel an increase in their general stamina or endurance.

Alternatively, if an arm ergometer or exercise bicycle is used, the same basic principle can be utilized, calculating distance pedaled or time spent actively pedaling the ergometer or exercise bicycle. The individual begins his aerobic or non-fatiguing general conditioning exercise program at 20% of maximum exercise capability three to four times per week for one month before increasing the distance by 10%. He continues with that level of activity for another month before increasing by another 10% so that he is exercising at 40% of maximum exercise capability. For example, if an individual is able to pedal an exercise bicycle for one mile or is able to actively pedal the bicycle for up to 20 minutes, then that is his maximum exercise capability. He is instructed to begin his exercise program at one-fifth of a mile (or if time is used, then four minutes is the beginning exercise time). This is repeated three to four times per week for an entire month before increasing the distance pedaled to one-third of a mile or six minutes. Our patients are encouraged to stick with that for an additional month before increasing by another 10%, and so on.

Individuals are cautioned to stop if they become fatigued during their exercise program, or if they experience pain or achiness in their muscles. Most polio survivors are able to continue increasing their exercise program to nearly the maximum exercise capability, though it clearly would take a full nine months if this program were strictly followed. Conditioning or aerobic exercise at this submaximal level allows the individual to regain a healthier sense of stamina without damaging delicate old motor units.

Additionally, it is imperative to incorporate the concept of pacing and spacing within the non-fatiguing general conditioning exercise program. This means that rests are to be taken during the exercise program every few minutes.

The 20% rule is sometimes also applied to polio survivors when they are given instructions in a home flexibility and stretching program so they do not exercise too vigorously.

This exercise program can be modified somewhat with the supervision of a physical therapist, depending on the progress made by the polio survivor. This program may not eliminate fatigue for all polio survivors, but we have found it effective for those who have a significant element of deconditioning contributing to their sense of fatigue. It has also been quite useful for polio survivors to use as an exercise guideline following surgery, illness, myocardial infarction, or trauma.

PART I A Case for Re-evaluating Physical Therapy as a Viable Extended Treatment for Polio Individuals in the 1990's

Sandra Hughes Grinnell, Independent Medical Researcher

Since writing about my history of polio in an article entitled "**A Post-Polio Normal's Reconciliation with the Ghost of Polio Past**" in two parts for the Fall 1989 and Winter 1990 issues of *Polio Network News*, I have gained stamina and muscle strength going significantly beyond what I had summarized at that time. Several post-polio normals wrote to me indicating that I had helped them to establish more credibility in linking their stamina problems to "old polio." Therefore, I decided that if I wrote an update article, I might now be able to help polio survivors take a more credible stand in convincing their doctors and/or insurance companies of the viability of utilizing physical therapy as an "extended treatment" program. Such a program would draw, in part, on the "acute care" philosophies from years ago stressing exercises geared to the patient's individual tolerance and which avoid aggressive overtreatment of muscles.

I attribute my steady progress during the past two years to professional physical therapy treatments (utilizing hot packs, cold packs, massage, ultrasound and electro-stim, as well as some traction treatments, where indicated) coordinated with deep breathing and slow muscle stretching as a form of muscle conditioning exercise. In the early months I did these as often as three times a day, holding each repetition for 15 to 20 seconds so that my steadily improving muscle tone would not have a chance to start to atrophy and regress. Also, after establishing a 1/4" leg length discrepancy, I began using a 1/4" heel lift for my left leg all the time, making walking virtually pain free. My rest periods are now fewer and shorter and the need for applying heat and/or cold packs to sore and swollen muscles is far less frequent. Also, with continued intermittent therapy treatments, I am now riding a stationary bike with some resistance every day for 20 minutes as opposed to the five minutes a day with no resistance every day in 1989. Most recently, I have been experiencing corresponding increases of strength in my quadriceps. (Breaking up all potentially repetitive activity, be it active or sedentary, with frequent postural changes increases my overall stamina.)

Now, if I were to go on, in this article, to give you the step by step details of my physical therapy program

including all the things I did to reinforce my progress, it would be a book in itself. In my opinion, it would have been more self-serving than helpful because it just seemed impossible to establish whether the other post-polio population's physical problems including my own could be traced directly back to our original bout with polio. However, it is likely that "old polio" has indeed aggravated and/or complicated the way our bodies responded to various additional physical illnesses and/or emotional stress for the past 30 plus years. Because of all these variables, it would be extremely difficult for me to say that my specific plan for physical therapy would be efficient for all survivors to consider. I decided that what I could do is share with you the key factors that helped me develop and shape the mental attitudes that lead to the formulation of a physical therapy approach right for me. along with what motivated me to do whatever I had to do to reach my goals and keep setting new ones. I believe that these key factors can be utilized to varying degrees by all survivors, no matter what the degree of disability.

My minor in college was psychology with emphasis on the study of behavior modification techniques. In the early 1980's I was a group leader in a weight loss clinic which utilized these techniques. We suggested that clients keep a food journal and begin to tune into individual life-style behavior patterns which could be linked to food consumption. Today, there is a significant body of medical research showing that our biochemical makeup involves a complete inter-relationship between the mind and body in a very real physical sense. When I started having post-polio problems it was natural for me to question my own life-style habits and behaviors because of my experience working in a weight clinic helping people who were searching for reasons as to why their weight had gotten so out of control. This time, however, I did so in ways that included the body mechanics of how I used and/or misused my physical body for the past 30 years creating what many erroneously perceive a "sudden" loss of strength and stamina from old polio.

I want my ideas to inspire those of you reading this, who are survivors, to question your own behavior patterns and to create your own personal strategy for gaining more control over your bodies again. At the same time it is important to me to present suggestions in such a way as to help you establish a balance between being optimistic, yet realistic. in setting goals based on your own highly individual medical histories. Therefore, the remainder of this article will be an itemized outline of the key factors that have helped me and that I hope you will find useful, including a description of reading materials you may want to consider devoting some time to.

1. DEVELOPING AND SUSTAINING

MOTIVATION — When I was in training to become a weight therapist in 1980, I was fortunate to have had an exceptional instructor in behavior modification. What made him a truly a gifted person was his ability to inspire others to develop the motivational tools needed to make significant life-style changes. Fortunately for you today, there is another man, Anthony Robbins, who has written a best selling book entitled *Unlimited Power*, Ballantine Books, 1986, paperback. The truth is that to become motivated something has to happen inside of your brain that gives you a clear and realistic picture of the end results you would like to achieve and how great you would feel as a result of your efforts to initiate change and create a tangible plan of action. I cannot effectively teach you behavior modification techniques in the space of this article. Even if I could, it would not come close to the knowledge you will get out of Mr. Robbins' book. Quite frankly, I have never read a more useful text on how to effectively motivate yourself to excel in every facet of your life. Some of the most useful sources he cites are, in fact, people with disabilities. Mr. Robbins is endorsed by medical specialists in every field, as well as business professionals, athletes, and teachers.

2. THE ART OF VISUALIZATION — Sister Elizabeth Kenny had no medical training or much formal education of any kind. As a matter of fact, she passed herself off as a nurse in a home-made uniform when she first began to treat acute polio patients with her techniques in her native Australia. Although there were some serious flaws in parts of Sister Kenny's work (which I will write about later in this article), I could not help but wonder how she came up with the wonderfully innovative orthopaedic concepts which were correct and that made her famous the world over. I found an in-depth article about her life in the November, 1981, issue of *The Smithsonian* by Victor Cohn, a medical reporter. The article is entitled "Sister Kenny's fierce fight for better polio care" and, in part, it said about her: "when she was 16 years old she became concerned that her little brother Willie was too frail. She wrote for advice to a surgeon named Aeneas McDonnell who had treated her when she was 13 years old for a broken wrist. He responded with a series of letters lecturing her on muscle structure. She then rigged up a wooden man with strings to show Willie how his muscles worked." Years later when confronted with children suffering from a strange disease called polio, she was able to visualize the child from the inside by drawing on the knowledge she gained at age 16 when trying to help her brother with his own muscle weaknesses. That ability, combined with her fiercely determined personality, would lead to a re-evaluation in polio rehabilitation techniques.

I cannot think of a more profound example in the polio literature of how the art of visualization can be applied to all of us as polio survivors in order to appreciate the importance of learning how our muscles work (or do not work!) in order to help ourselves more effectively today.

It was through having access to physical therapy books in my local hospital medical library that I was able to visualize my own muscles better and begin to make additional progress. I was fortunate to come across a book entitled *Muscles: Testing and Function*, by Florence Peterson Kendall, P.T. and Elizabeth Kendall McCreary, B.A., Williams and Wilkins, 1983. This textbook had no specific references to neuromuscular diseases but in my quest to have a better visual understanding in my mind of my own muscles, I personally found the following pages from this book to be indispensable and potentially relevant for others to refer to in mapping out a physical therapy plan: pp. 166-167, 170, 187-188, 270-277, 288, 290-291, 296-297, 301. The chart on p. 296 illustrates among other things that for many people, barring contraindication, it is important to correct even slight leg length discrepancies, whether one has had polio or not. The book can be ordered from the publisher by calling 1/800/638-0672 or writing the publisher at 428 E. Preston, Baltimore, Maryland 21202 USA. This book at the very least will provide an excellent way for you to get a better understanding of how your muscles should work together. It will also help you to evaluate your problem areas more effectively, as not unlike Sister Kenny did, you begin to "see your muscles from the inside out."

3. ESTABLISHING PATTERNS OF MUSCLE TIGHTNESS AS WELL AS MUSCLE WEAKNESS IN THE POLIO LITERATURE — Thinking back to the article on Sister Kenny in *The Smithsonian*, I wondered what Kenny's book entitled *The Kenny Concept of Infantile Paralysis and Its Treatment* co-written with Dr. John Pohl, Minneapolis General Hospital in 1943, had to say about muscle tightness. For a woman so famous the world over, I wondered why we seldom see references to her work by polio specialists. I had heard stories about doctors either completely rejecting her work from the start — never reading her book or implementing her therapy with their patients at all; or the reverse was true with over zealous doctors ordering over-stretching of tight muscles resulting in more pain! I had gotten a few clues from the 1981 article in *The Smithsonian* (well worth your reading) which stressed her incredible "arrogance" in dealings with doctors — even those she had collaborated with on her book!

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A Case for Re-evaluating Physical Therapy *(continued from page 7)*

Upon reading her book for myself, I was generally impressed by the fact that she did indeed emphasize the importance of stretching tight muscles as well as "re-education" to restore mental awareness of muscles that were not irreversibly damaged by the disease process, in addition to applying moist heat. Unfortunately, instead of devoting the book exclusively to her physical therapy concepts, she weaves a whole new theory on the basic pathology of the disease. Dr. Jacquelin Perry, Rancho Los Amigos, Downey, California, wrote to me on the subject of Sister Kenny's book in September, 1990, in part as follows: "I am very familiar with the Pohl-Kenny book. I am also very familiar with Sister Kenny's concepts and techniques as I was a physical therapist in World War II at the time she came to this ... The reason she was not accepted is because she insisted that the basic pathology was in the tight muscles ... the reality is that the pathology is in the anterior horn cells ... The major contribution that Sister Kenny made to the acute care of polio was a more effective means of pain relief ... These are very valuable contributions ... her clinical program was excellent but she was not a pathologist." In a telephone conversation recently with Florence Kendall, P.T., she agreed with Dr. Perry, adding that one of the problems she and her husband had with Sister Kenny's work was the complete omission of the subject of muscle strength testing. Another major concern of the Kendalls was Sister Kenny's failure to use appropriate splints and braces.

Keeping Dr. Perry's and Mrs. Kendall's input clearly in mind, I believe it is worth your time to read Kenny's work even with its shortcomings just for historical perspective because for all of her arrogance and some of her mistakes, she was undeniably responsible for igniting controversy which drew attention to the after-care of polio patients that in balance benefited us all.

The book is out of print, but you can get existing copies through inter-library loans or perhaps an older physician in your community may have a copy you can borrow.

Florence Kendall, P.T., and Elizabeth Kendall McCreary, B.A., also had a recurrent theme in their 1983 textbook, cited previously, which emphasized the problems that arise from short tight muscles opposing weak stretched muscles in otherwise "normal" patients. Since so much of the book was useful in working with my physical therapists on my polio problems, I wanted to know more about Florence Kendall. I knew that some years ago she had been a highly respected instructor in Body Mechanics

at Johns Hopkins Hospital, School of Nursing. Through the hospital I was able to get in touch with her, and I was pleased to learn that she and her husband, Henry O. Kendall, also a physical therapist, had in fact co-authored a booklet in 1938 entitled **Care During The Recovery Period In Paralytic Poliomyelitis** prepared by direction of the Surgeon General of the United States Government. She forwarded a copy of the 1939 revised edition to me, and I was fascinated to see that the pages from **Muscles: Testing and Function**, that she co-authored in 1983 for patients in general that I found so useful, were in fact dealing with some of the same specific areas that were outlined in part in the 1939 revised booklet I read. Those pages from the booklet are as follows: pp. 5-7, 14-21, 86-89, 94-95. Notably, the charts on pp. 87-89 on stretching tight muscles are well worth taking a look at again.

Ms. Kendall also forward to me an article she co-authored with her husband in 1947 entitled, **Orthopedic and Physical Therapy Objectives in Poliomyelitis Treatment**. It appeared in *The Physiotherapy Review*, Vol. 27, No. 3, May-June, 1947. Upon reading the article, I felt that it would be invaluable to post-polio individuals and their doctors by providing them with some common sense general guidelines based on scientifically correct medical data and clinical experience which could be utilized and "individualized" for specific needs in post-polio care today. On pages 4-5, for instance, there is an excellent discussion on muscle weakness and imbalance outlining how to determine when muscle stretching is appropriate and, at the same time, why and how to avoid over-stretching tight muscles. Ms. Kendall, who has 50 plus years experience in the field of body mechanics has agreed to let the International Polio Network in St. Louis distribute the seven page article in its entirety to all who would like a copy.* In my opinion, Ms. Kendall fills an important void that Sister Kenny left due to the controversy in medical circles which surrounded her work before and after her death in 1953. I am optimistic that all of the works I have cited in this article will be seriously reviewed by polio specialists and therapists and ultimately help many other as much as they have helped me.

Due to space limitations, **Part II of A Case for Re-evaluating Physical Therapy as a Viable Extended Treatment for Polio Individuals in the 1990's** will be published in the Fall 1991 issue of *Polio Network News* (Vol. 7, No. 4). If you are interested in trying some of **Sandra Hughes Grinnell's** ideas and do not wish to wait for the second half of her article, please send \$2.50 (for photocopying and postage) to

*Send a self-addressed stamped (.29) business-sized envelope to International Polio Network, 4502 Maryland Avenue, St. Louis, MO 63108 USA.

International Polio Network, 4502 Maryland Avenue, St. Louis, MO 63108 USA for a complete copy. Sandra feels very strongly that the second half of the article contains important information for a successful program. It includes [Combining Advice and Creating a New Strategy; Re-Mastering the Art of Deep Breathing — We All Can Improve, and How to Get the Most Out of Your Physical Therapy.](#)

CDC Study (continued from page 1)

Second, a paper and pencil questionnaire that will predict a person's chances of having a potentially problematic secondary condition was created. This "screening instrument" still needs much testing before it can be formally endorsed as consistently accurate and useful, but once it is refined, it could be used for several purposes. A polio survivor could fill it out at home and take it to his/her doctor's office to validate specific post-polio problems. It could also serve as an initial stimulus for seeking medical help if one is not sure whether insidious new symptoms are real or imagined. This questionnaire could prove helpful to clinicians examining persons with a history of polio. Answers to questions on the questionnaire could make physicians quickly aware of the likelihood or risk of an individual patient having the conditions before he/she is examined, ultimately saving valuable diagnostic time and costs.

Third, several characteristics of this group of polio survivors were studied in greater depth. Based on these "focused investigations," some new information is available and preliminary conclusions can be drawn about recommendations for good health care practices.

Depression When depression was found in post polio persons, it seemed to be a result of circumstances that were independent of their history of polio, including their levels of disability. Depression occurred in people who had a tendency to view life pessimistically. It appears that the old adages to "look for the silver lining" and on the "bright side" of negative events pays off. How a person deals with anger also affects his/her level of depression. People who were able to express their anger at a particular event, and then think through how to remedy the distressing situation were less depressed than people who held in their anger or simply vented their anger. It is especially not recommended to suppress anger. Persons who are depressed are advised to seek professional counseling.

Glutathione Glutathione (GSH) is an amino acid that is responsible for many of the body's important cellular processes and seems to be associated with

healthy aging. Among the less disabled polio survivors, the better a person's health was, the higher the GSH levels. But among the more disabled polio survivors, the poorer a person's health was, the higher the GSH levels. This finding suggests that these persons with more involved disabilities may represent "super-survivors" who were enabled to live many years with their severe muscle impairments aided by their higher GSH levels. Since GSH is present in vegetables containing vitamins A, C, and B6, dietary intake of such foods may be beneficial.

Cardiac Risk Factors An elevated cholesterol ratio was found in 36% of participants and 62% had an exercise capacity below that which would be expected. "Reduced exercise capacity" is associated with reported functional declines, and may account for new lack of endurance and inability to perform accustomed tasks. Prevention efforts that focus on improved diet and individually designed exercise plans are recommended for polio survivors.

Hand and Wrist Problems Polio survivors often have to use their hands and wrists more than non-disabled persons to perform the average day's activities. This group's frequency of nerve problems in the hand and wrist (77%) is far above that reported in the general population. Persons with mild or moderate disabilities (those who use canes or crutches, especially) are more likely to develop carpal tunnel syndrome and osteoarthritis in the upper extremities than polio survivors who use wheelchairs. It is recommended that people who use canes, crutches, or manual wheelchairs consider switching to electric mobility vehicles if they are experiencing or are at risk for these conditions. Further study of how to alleviate and prevent post-polio hand/wrist problems due to overuse is needed.

Perceptions of Polio Survivors Physicians rated twice as many participants as "moderately or severely disabled" compared to how polio survivors rated themselves based on their abilities to get around. Survivors also tended to rate themselves as having normal muscle strength in limbs that were found to be weaker than normal according to standard measures. Polio survivors, therefore, described themselves as a little stronger and less disabled than they were perceived to be.

For a copy of the entire 204-page final, technical research report, contact Mr. Larry Burt, Program Coordinator, Disabilities Prevention Program, Centers for Disease Control, Mailstop F-41, Atlanta, Georgia 30333 USA (404/488-4905).

Polio Awareness

International Polio Network wishes to thank **Congressman John T. Doolittle** of California for introducing House Joint resolution 211 declaring June 1-7, 1991 as National Polio Awareness Week. A special thank you to all survivors who requested their representative to co-sponsor the resolution. The co-signers are listed below.

Co-Sponsors of National Polio Awareness Week

Jim McDermott, Jerry Lewis, William Lipinski, Cardiss Collins, Marge Roukema, James Walsh, Raymond McGrath, Mike Espy, Bob Clement, Ike Skelton, Larry Smith, Amo Houghton, James Hansen, Charles Rangel, Matthew Martinez, Gus Savage, Frank Riggs, Jaime Fuster, Carlos Moorhead, Floyd Spence, James Quillen, Bruce Vento, Jose Serrano, Steven Schiff, Charles Wilson, Martin Lancaster, Glenn M. Anderson, William Jefferson, Wayne Owens, Glenn Poshard, Scott Klug, John LaFalce, George Brown, Eliot Engel, Eleanor Norton, Jolene Unsoeld, Tom Bevil, Bob Stump, Elizabeth Patterson, Marty Russo, Gerald Kleczka, James Bilbray, Jim Slattery, George Hochbrueckner, Bill Sarpalius, Albert Bustamente, Robin Tallon, Sid Morrison, John Conyers, Ron de Lugo, Ronald Dellums, Jamie L. Whitten, George (Buddy) Darden, Hamilton Fish, Richard Gephardt, Joe Kolter, Nick Rahall, Larry Smith, Bill Emerson, Peter de Fazio, Norman Mineta, William Gooding, Beverly Byron, Barbara Boxer, Mel Levin,

Bart Gordon, Leon Panetta, Paul Henry, Thomas Petri, Don Sundquist, Peter Kostmayer.

The number was short of the amount needed to officially declare National Polio Awareness Week and each year it becomes more difficult to garner sponsoring. Rep. Dave McCurdy, Oklahoma, has spent several years trying to get Congress out of the commemorative business. Of the 650 laws passed during the 101st Congress, 30 percent were commemorative. For each one, House members or their aides have to round up a majority of members to co-sponsor the measures in order to get it considered by the House Committee on Post Office and Civil Service. An informal survey by his office revealed that one-tenth of all House members have adopted a policy of not sponsoring commemoratives and 45 percent ranked commemoratives as "dead last among their priorities."

McCurdy is proposing legislation to establish an independent commemorative commission that would advise the president on proposed commemoratives. The subcommittee that handles the commemoratives has polled House members for ideas on a "fair, more efficient and worthwhile" process for handling the bills. The results are expected soon.

Source: UPI

Post-Polio Directory 1991

Please add the following:

HEALTH PROFESSIONALS

David S. Bradford, M.D.
Department of Orthopaedic Surgery (U 471)
University of California
San Francisco, CA 94143-0728

Steven M. Moskowitz, M.D.
Physical Medicine and Rehab
New England Rehab Hospital
1 Rehabilitation Way
Woburn, MA 01801
617/935-5050

Jeanne Edwards, M.D.
Ashok Kache, M.D.
Rodney Myers, M.D.
Charles J. Laenger/Rehab. Engr.
Kaiser Rehabilitation Center
1125 South Trenton
Tulsa, OK 74120
918/560-5798

CLINICS

Sunnyview Rehab Hospital
Steven Jarrett, M.D.
1270 Belmont Avenue
Schenectady, NY 12308
518/382-4560

SUPPORT GROUPS

Post-Polio SG of Port Charlotte
Jane E. Swan
3095 Yukon Dr.
Port Charlotte, FL 33948
813/627-4520

Bonnie Jo Shippen
2889 Hillview Drive
Yuba City, CA 95993
916/674-0998

Mid Michigan Post-Polio SG
Jean Iutzi
5754 N. Rodgers Ave.
Harrison, MI 48625

Yakima Valley Polio Network
Connie Ingram
Rt. 3, Box 3510
Prosser, WA 99350
509/786-4126

Please make the following changes:

CLINICS

O'Donoghue Rehab Institute
David W. Kent, M.D.
1122 N.E. 13th Street
Oklahoma City, OK 73120
405/271-3636

Patricia Neal Rehab Center
Jeffrey S. Hecht, M.D.
1901 Clinch Ave., Ste 301 East
Knoxville, TN 37916
615/541-1167

SUPPORT GROUPS

Alabama Post-Polio Ventilator Users SG
Lilly Henderson
3327 Meadow Lane
Montgomery, AL 36116-3027

Post-Polio SG of Greater Fort Lauderdale, Inc.
Edi Tuholske
3050 N.W. 42nd Ave. C-209
Coconut Creek, FL 33066

NE Oklahoma Post-Polio SG
Sue Sharp, RNC, BSN
Hillcrest Center for 55+
3220 South Peoria
Tulsa, OK 74105
918/744-5595

Central VA PPSG (Richmond)
Mary Wilkinson
P.O. Box 70
St. Stephens Church, VA 23148

INTERNATIONAL

PPASS of British Columbia
P.O. Box 6578, Depot 1
Victoria, BC V8P 5N7
Canada

The Swedish Association of Persons Disabled by Accidents
Box 2031
171 02 Solna
Sweden

Please delete the support group in:
Burlington Co., Fort Dix, NJ

In another attempt to promote awareness, International Polio Network received the following letter:

THE SECRETARY OF HEALTH & HUMAN SERVICES
WASHINGTON, DC 20201
May 28, 1991

Ms. Joan Headley, Executive Director
International Polio Network
4502 Maryland Avenue
St. Louis, Missouri 63108

Dear Ms. Headley:

I am pleased to recognize the week of June 1 through June 7, 1991 to promote awareness of polio and its late effects and to offer my support to those brave polio survivors across the country.

Today there are an estimated 650,000 paralytic polio survivors in the United States. Many of them suffer from post-polio syndrome, a recurrence of polio's symptoms decades after the original illness, even though no polio virus is present in the body. In addition to pain, fatigue, and muscle weakness, symptoms can include difficulty in sleeping, breathing and swallowing, and rarely, respiratory problems. Having overcome polio once, post-polio patients often experience intense emotions such as denial, anger, frustration, and hopelessness as they must once more learn to accept and cope with new limitations.

No cure exists for post-polio syndrome, but it can be treated with a regular exercise program, physical therapy, weight loss, and drug therapy, such as anti-inflammatory drugs. Most patients can adapt and improve the quality of their lives if they rest when tired, exercise moderately, control their weight, and avoid smoking and drinking alcoholic beverages.

Scientists cannot explain what causes polio's symptoms to recur nor why the syndrome targets some people and not others. Thanks to dedicated investigators supported by such Federal agencies at the National Institute of Neurological Disorders and Stroke, we continue to learn more and more about polio and its late effects.

Much remains to be done, however. The Decade of the Brain provides exciting new opportunities to discover the answers to the mysteries of polio and its late effects — knowledge critical to the development of new treatments — and ultimately, to our ability to conquer polio once and for all. Working with the National Institute of Neurological Disorders and Stroke are voluntary health organizations such as the International Polio Network. I commend your efforts to wage a three-pronged attack on polio through support of research, patient support, and public education. Your enthusiasm and accomplishments are fundamental to our ability to help understand and meet the challenges created by this complex disorder.

My thoughts are with you and you have my very best wishes for continued success.

Sincerely,
Louis W. Sullivan, M.D.

Update on Funds for Research

As reported in the last issue of *Polio Network News*, **Lauro S. Halstead, MD**, testified this Spring before the Senate and House Appropriations Subcommittees for Department of Labor, HHS, and Education, requesting major funding for post-polio research. In addition to you, our readers, health professionals and support groups from the 26 states represented by legislators on the subcommittees were asked to write letters and make phone calls urging the Subcommittees to direct the National Institute of Neurological Disorders and Stroke (NINDS) and the new National Center for Medical Rehabilitation Research (NCMRR) to issue specific requests for applications (RFAs) for three million dollars to investigate the causes of post-polio syndrome and the most effective treatments.

In June, the staff of **William Natcher** (D-KY), the Chair of the House Subcommittee, and **Ernest Hollings** (D-SC), member of the Senate Subcommittee, assured Dr. Halstead that the request for funds (RFAs) will be written in the 1991 final report.

In July, the House Subcommittee adopted a report which includes a statement on the need to support research on the late effects of polio. Unfortunately, the statement only suggests that funds be spent and does not indicate the need to issue specific requests for applications (RFAs). The Senate Subcommittee report, also issued in July, includes Dr. Halstead's testimony almost verbatim. It states the need to support post-polio research and requests that RFAs be issued by NIH (specifically the NINDS and NCMRR). No specific dollar amount was issued at this time.

The next challenge is to ensure that adequate funding is allocated by NIH. As we move toward fiscal year 1992, efforts will continue to educate and solicit members of Congress so that the language adopted by the Appropriations Subcommittees is translated into actual RFAs being issued.

Dr. Halstead; Charles Harles, a disability rights lawyer and lobbyist; Jessica Scheer, a medical anthropologist; and Hugh Gallagher, author of *FDR's Splendid Deception*, have coordinated this campaign over the past two years with support from members of the Washington-based Polio Society.

YOU CAN HELP AGAIN! The team requests that you thank your legislators for their continued help in securing major funding for post-polio research. In your thank-you letters, ask them to urge Dr. Murray Goldstein, Director of the NINDS, and Dr. Duane Alexander, Acting Director of the NCMRR, to issue RFAs on post-polio issues in fiscal year 1993. For more information, call Jessica Scheer, PhD (301/897-8180) at the Polio Society.



CALENDAR

Mississippi Polio Survivors Association Quarterly Meeting, Busey Auditorium, Baptist Medical Center, Jackson, MS USA, September, 14 1991. Contact: Robert Thayer at 601/924-9284.

Second Colorado Post-Polio Educational Conference, Westin, Denver, CO USA, September 13-14, 1991. Contact: Alison Kron (303/233-1666).

The Second Texas-Oklahoma Post-Polio Symposium, Wichita Falls Ramada Inn, September 21-22, 1991. Contact: Barbara Miller, 4503 Allison, Wichita Falls, TX 76308 USA (817/691-3497).

Third Provincial Conference on Post-Polio — The Late Effects, Holiday Inn South, 1330 Pembina Highway, Winnipeg, Manitoba, Canada, September 27-28, 1991. Contact: Post-Polio Network, Inc., c/o Canadian Paraplegic Association, Inc., 825 Sherbrook St., Winnipeg, Manitoba, R3A 1M5, Canada.

Management Techniques for Post-Polios, Southeast Area Vo-Tech Building, Sioux Falls, SD, October 5, 1991. Contact: Tri-State Polio Survivors, Box 88941, Western Mall, Sioux Falls, SD 57105-8941 USA.

Greater New York Post-Polio Conference, Marriott Hotel, Uniondale (Nassau County), New York USA, Sunday, October 13, 1991. Contact: Mike Kossove, Touro College (516/351-8888).

Polio Educational Conference, Crystal Gateway Marriott Hotel, Crystal City, VA, October 25-26, 1991 (morning session sponsored by The American Academy of Rehabilitation Medicine; afternoon and evening sessions sponsored by Polio Society). Contact: Jessica Scheer, PhD, Polio Society, 4200 Wisconsin Ave., NW, Suite 106273, Washington, DC 20016 USA (301/897-8180).

Post-Polio Syndrome — What Is It?, Holiday Inn (I-75 and 40), Ocala, FL, November 9, 1991. Contact: Carolyn Raville, 7180 SW 182nd Court, Dunellon, FL 32630 USA (904/489-1731).

The Late Effects of Polio, BEH Auditorium, Mercy Hospital, Des Moines, IA, March 27-18, 1992. Contact: Norma Cornelius, Iowa Polio Survivors Group, 1319 Johnson Ave., Ames, IA 50010 USA (515/232-7237).

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“Networking is indeed the power and joy of working together. Our International Polio Network is a wonderful example of what can be accomplished by caring and sharing.”

Gini Laurie, June 1986
Meriden, Connecticut

GINI LAURIE ENDOWMENT

The Board of Directors and the staff of Gazette International Networking Institute (G.I.N.I.) are diligently working to continue Gini Laurie's lifelong work. On the second anniversary of her death, we seek your continued support by asking you to contribute to The Gini Laurie Endowment, G.I.N.I., 4502 Maryland Avenue, St. Louis, MO 63108 USA. Because G.I.N.I. is a nonprofit 501(c)(3) organization, your contribution is tax-deductible.

Please add my enclosed contribution of \$ _____ to Gini Laurie Endowment.

Name _____

Address _____

Use \$25.00 for my annual subscription fee to *Rehabilitation Gazette*, *Polio Network News*, and *I.V.U.N. News*, and the *Post-Polio Directory*.

