



EMG: WHAT, WHY, AND WHY NOT

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WHAT IS AN EMG STUDY?

An electromyogram (EMG) is a diagnostic instrument that detects the presence of motor units. (A motor unit consists of the nerve and all the muscle fibers it stimulates.) In the diagnostic EMG, a very small diameter needle is inserted into a muscle.

In an EMG study, a number of observations are made. First, any spontaneous resting activity is noted while the individual is completely relaxed. Normally, no resting activity should be present. If abnormal activity is observed with the muscle at rest, a neuropathy (a disease of the nerves) or myopathy (a disease of the muscles) may be the cause of the problem.

Next, the polio survivor is asked to contract the muscle up to full effort. During this phase of the examination, the readings of the individual being tested are compared to the readings of normal motor units, which fall within a given size range and with a maximum number of phases. Motor units which have too many phases (polyphasic) and are larger than normal could indicate a neuropathy. On the other hand, if smaller than normal motor units are observed which are also polyphasic, a myopathy may be indicated.

Additionally, the EMG can document the rate of recruitment (the rate at which the number of motor units are activated) and degree of interference at full effort. Incomplete interference at full effort can indicate the severity of the neuropathic or myopathic process.

The second part of what is commonly referred to as an EMG study is the nerve conduction study (NCS) in which surface electrodes are used. In the NCS, a controlled electrical shock at a certain threshold stimulates the nerve. At the end of the arms and legs,

the time delay from onset of stimulus to the response is termed the distal latency. In some neuropathies, for example, carpal tunnel syndrome, this time delay is extended.

Also, the nerve conduction speed can be calculated by stimulating a nerve at two points. A lower speed may be found in a systemic disease, such as diabetes mellitus. A slower nerve speed in one section may be

found when a nerve is compressed, for example, across the elbow.

Data from the EMG and NCS is combined and the determination can be made whether a neuropathy or myopathy is present and whether it is acute (is presently active) or chronic (occurred in the past but is no longer active). Further, it can be determined whether the problem is localized or generalized throughout the body. Finally, the severity of the problem can be estimated. The EMG of polio survivors will typically show evidence of chronic neuropathy which reflects

the paralysis of many years ago.

WHAT IS THE VALUE OF AN EMG STUDY?

For those who have had paralytic polio, an EMG study will detect evidence of the prior effects of polio. This will also be true of those who had initial paralysis or weakness and experienced complete clinical recovery. The apparently complete recovery that occurs in those instances, and partial recovery that occurred in those with greater involvement, resulted primarily from a process that has been termed collateral reinnervation or "sprouting." After the acute episode of poliomyelitis, various areas of muscle are "orphaned" of nerve supply as a result of the motor nerve cells that did not survive the viral attack.

"Well-founded research studies have established that EMG findings of polio survivors who have been appropriately diagnosed with post-polio syndrome, and those of survivors who are not experiencing symptoms, are not significantly different."

Depending on the relative number of motor nerves surviving, these surviving motor units (in the areas of their terminal sprouts) send out sprouts to the orphaned muscle tissue. As a result, much larger than normal motor units are formed.

This process which occurs months after recovery from acute polio results in functional improvement for the polio survivor. Therefore, an EMG study of an individual who had paralytic polio will show much larger than normal motor units. Characteristically, these motor units also will be polyphasic. This finding in polio survivors is termed chronic polyneuropathy. These findings reflect only a past pathology and do not indicate that anything is currently active.

A question that has been asked by many polio survivors is whether an EMG can detect the presence of post-polio syndrome. A straightforward answer to this question simply is that an EMG is of no value whatsoever in detecting post-polio syndrome. Well-founded research studies have established that EMG findings of polio survivors who have been appropriately diagnosed with post-polio syndrome, and those of survivors who are not experiencing symptoms, are not significantly different. It is well established among medical practitioners experienced in managing post-polio patients that the diagnosis of post-polio syndrome is a clinical diagnosis. No objective test is available that can reliably and specifically denote the presence of post-polio syndrome. The diagnosis is made only after well-established clinical criteria have been met, and other possible medical conditions that could also cause symptoms of progressive fatigue, weakness, and pain have been excluded.

PAUL E. PEACH, MD, has written numerous articles relating to post-polio issues including a chapter entitled "Late Effects of Poliomyelitis in Clinical Aspects of Rehabilitation Medicine," has published original research, and has presented at many post-polio conferences.

Dr. Peach has recently established the Palmyra Post-Polio Clinic in Albany, Georgia, which provides comprehensive services to polio survivors, and previously served as medical director at Warm Springs. He may be reached at Rehab Associates of South Georgia, Inc., 810 Thirteenth Avenue, Suite 105, Albany, Georgia 31701 (912/434-2551).

If an EMG is of no value in diagnosing post-polio syndrome, then under what circumstances would performing an EMG be justified on an individual who is being evaluated for post-polio syndrome? In the post-polio clinics I have developed, I have never used EMG studies as a screening test, but rather, utilize them with a specific purpose in mind, and only to the specific limbs which may yield maximum diagnostic benefit. The reasons for this are twofold: the EMG-NCS is not an inexpensive test, and the majority of polio survivors will endure some degree of discomfort from these procedures.

I will recommend an EMG in two situations. Generally, it is preferable to have medical records available to confirm a history of paralytic poliomyelitis. However, this frequently is not feasible. If a person gives a history compatible with acute poliomyelitis, and he or she presents with obvious atrophic paralysis with complete sensory preservation, a history of poliomyelitis is supported, and an EMG is unnecessary. If no residual paralysis is clinically apparent, however, then an EMG is useful to confirm the presence of chronic polyneuropathy (or earlier acute poliomyelitis as evidenced by large motor units).

Occasionally, someone is seen who had been misdiagnosed with poliomyelitis. If, for example, someone has spastic paralysis rather than flaccid paralysis (as seen in polio), or if sensory impairment is present, this is not consistent with a history of poliomyelitis and an EMG is helpful in determining the existence of another disorder.

Another situation where an EMG is appropriate is when, during the clinical evaluation, there is reason to suspect the coexistence of another disorder other than post-polio syndrome or chronic poliomyelitis. For example, carpal tunnel syndrome is much more common among crutch walkers than the general population. In persons with diabetes mellitus, for example, fatigue, and often sensory impairment, may also be present. An EMG-NCS is very useful in confirming the presence of these as well as other non-polio related disorders. Sometimes follow-up EMGs at a reasonable interval can be useful in monitoring response to clinical interventions, or, in some cases, confirming the progress of a disease process such as neuropathy of diabetes, carpal tunnel syndrome, or radiculopathy (a "pinched" nerve).

In summary, the EMG-NCS is a diagnostic study that can be very useful during the evaluation and clinical management of post-polio survivors. It does, however, as with any other diagnostic test, have its limitations. When utilized appropriately, it can be of very material assistance to the clinician in the evaluation and management of polio survivors. ❖

SURVIVAL OF THE UNFITTEST

ELLEN FAY PEAK, BIRMINGHAM, ALABAMA

Survival of the Unfittest? Because it demonstrates my approach to medical problems, I'll begin with the introduction to my article "Dealing with Breast Cancer" in the Fall 1995 issue of *Polio Network News*:

When I was diagnosed with cancer in my right breast on March 2, 1995, my first thought wasn't, "Am I going to die?" but, "Am I going to be able to type and feed myself?" And on April 3, when the surgeon whom I ultimately chose first examined me and said, "I've looked at your tests and agree that you do have cancer and that it will have to come out," I responded, "No, it doesn't have to come out."

Although I wouldn't have been surprised if he'd asked "Then why are you here?" he listened as I explained the history of my arm and shoulder limitations and watched as I, naked from the waist up, demonstrated my narrow range of arm and hand use, so narrow that I need full-time physical care.

The rest of my article dealt with tests to determine if the cancer had spread; talks with many medical experts, including both my primary-care physician and my polio specialist, as well as the anesthesiologist and his assistant; and a double mastectomy, twice the surgery that I'd started with. Why? The other breast looked as if it might go the same way in a few years; and I feared that leaving one breast would affect my already precarious balance.

After the article appeared, I received comments both praising and condemning my "attitude." If the reader found my attitude positive, the comment was positive; if the reader found it negative, the comment was negative, in the vein of, "Who does she think she is, trying to second-guess doctors?" Actually, I wasn't trying to second-guess anybody: I was first-guessing everybody. And I was taught by a master of the process: Dr. Charles Irwin, Chief Surgeon at the Georgia Warm Springs Foundation, whom I first encountered in 1945.

The doctors in Birmingham had said they wouldn't perform surgery on my feet until I "had my growth," which would've had me endure additional years of pain from the sores on my ankles caused by their rubbing against the inside of my braces. But Dr. Irwin did the surgery then, when I was thirteen. Within months my ankles had healed, and I discarded one leg brace and the hated high-top shoes.

Later, during a checkup at Warm Springs, a young doctor suggested that my right arm would look better fused at the elbow into a palm-down position (following the onset of polio, it had settled into a palm-up position). Dr. Irwin said, "Why don't you ask her how she uses that hand?" The younger doctor asked me, and I demonstrated by hooking the middle finger of my left hand over my bottom teeth, lifting that arm with my head, and setting its elbow down into the up-turned palm of my right hand. I then used the strength of my right arm to maneuver my weaker left arm. The prettying-up surgery fell by the wayside.



Kay Haygood and Ellen Fay Peak

Another time I complained about hurting my left ankle whenever I fell forward. Dr. Irwin examined my braced leg, pushing the foot up and down. Turning to another young doctor, he asked, "What do you suggest?" The other doctor said, "I'd put stops on her shoe." "How many?" Dr. Irwin asked. "Two — a front and a back," he said. Dr. Irwin pointed out that the muscle that pulled my foot up was one of my strongest, and the muscle that pushed my foot down, one of my weakest. Therefore, I needed only the front stop to prevent my foot from being pushed upward in a forward fall; the back stop would impede my walking.

Warm Springs and Dr. Irwin have been significant and positive influences in my life; unfortunately, other influences have been less positive but no less significant, given what I learned from them. For example, I first discovered the dangers in a "public" hospital when I broke the femur of my braced leg in 1973.

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As I lay in the emergency room, an orthopedic doctor whom I'd never seen examined me and announced, "We'll put her in a long-leg cast, waist-high, and send her home." "No," I said. "My mother wouldn't be able to handle me."

He admitted me and put my leg in traction. The next morning, while I was still in a kind of shock, the RN who came to feed me breakfast slung my tray down and announced, "I hope you're a fast eater, because I'm a fast feeder."

A week of traction passed before I realized the doctors were probably using a standard load of weights on my left leg, the one connected to my fragile left hip. When I asked, they x-rayed both hips, saw the difference, and reduced the poundage.

Later, when I asked about inhalation therapy, they ordered it but also suggested I use a monkey bar to exercise. For several days, my mother put my hands up on it, and I did what I could. Then I developed chest pains. When tests found no heart trouble, the monkey bar was removed and the pains stopped.

Another difficulty arose once I was out of traction nearly four months later, the break not yet healed. My doctors assumed opposing positions regarding my brace: one wanted me to wear it through the night, to protect the femur; another wanted me not to wear it through the night, to stress the femur. Their boss sent me home.

Twice a day, my mother hot-packed and stretched my knee. She stood me up every couple of hours.

Although she did not attend public school, **ELLEN FAY PEAK** obtained her GED diploma in 1950, graduated Phi Beta Kappa from Birmingham-Southern College with BA in 1955 (French and Spanish majors) and MA in English in 1963. She was an editorial assistant for *The Progressive Farmer* magazine 1956-63; a teacher of high school English, French, and Spanish, 1963-66; and an instructor of English at Jefferson State Community College 1966-1991, when she retired.

Ellen is a member of the Birmingham (Alabama) Post-Polio Support Group and currently chairs that group's statewide forum coming up May 1-3, 1998. She also volunteers her time as an editorial critic to *Polio Network News*.

Then she and my brother walked me endlessly while supporting me around my waist.

When the orthopedic doctors pronounced me cured, although my leg was too stiff for me to drive and I was unable to move around well enough to return to teaching, I went to Warm Springs.

There I was anxious and defensive, bursting into tears if anyone even suggested that my mother leave my room. As bad as my experience in the public hospital had been, it would've been much worse if she'd not spent much of every day with me, particularly around meal times.

When the charge nurse asked, "What can you do for yourself?" I burst into tears again. "Oh, yes," she said, "You're a quad, so you need total physical care." Not ever having been told I was a quadriplegic, I said, "No, I'm not."

Surprised, she said, "You are. Both your arms and legs are involved, aren't they?" With that, she set up my schedule. My first stop was the doctor's office, where I received prescriptions for a new brace to fit my "new" leg and a glide-about chair I could maneuver with my right foot. The doctor directed my physical therapist to stretch my leg three times a day, walk me three times a day, and do mat work with me at least once a day until my leg was bending to a sitting position, ensuring I could drive again.

When I left Warm Springs two weeks later, I was ready to return to teaching after a nine-month absence — back in a wheelchair, but also "back on my feet," physically and mentally rehabilitated for the second time.

I next discovered the dangers in general rehabilitation hospitals. Because I had learned at Warm Springs about research indicating that "old" polios could wear out their muscles, when I began to experience unusual fatigue in 1978, I consulted one of the new breed of doctors. As I sat dressed and combed before him, he asked if I could tie my shoelaces. I answered, "Probably. But I don't." When he asked, "Why not?" I explained I didn't have enough strength to tie my shoelaces and teach my classes.

Then, I sent a student to the reference library of a local medical school to discover whatever she could about polio, new fatigue, etc. She returned with photocopies of a few articles from *The Lancet*, the only references she could find. Although the term "post-polio syndrome" was not yet used, these articles gave me the earliest concrete examples of what lay ahead.

The shoelace incident was the first time I'd had "to explain myself." In 1979, when my mother, who had tied my shoelaces, started her own decline, I called

several home-health providers, but none opened until eight o'clock, and they all closed on weekends. I applied to several nursing homes for a room and attendant care — I would continue teaching and supporting my mother — but was told I would be a disruptive influence and I couldn't rescue myself if the building caught fire in the middle of the night.

When my mother herself went into a nursing home, a colleague (Jeanne) moved in to her home and took on my physical care while I mulled over what to do next. We had some tense moments: I knew little about instructing another person in dressing me, and she knew even less about taking instruction.

"Just getting my support hose on took forever," I complained to Harriott, another colleague, in my office on the first work day I'd ever started without my mother.

As Jeanne had begun to dress me that morning, though, she'd been anxious to please. But she picked up the wrong hose first. My left leg being smaller than my right, I have shorter and longer hose, a difference we'd discussed the night before, but she'd forgotten it, and we had to start over. When she began to put on my left shoe (left hose/left shoe), she pulled the lace out of its double-laced pattern. By the time we'd gotten my shoelaces tied (snugly but not too), she was gritting her teeth.

Before telling Harriott about the next step, I launched into a defense of myself. Because I am an "upside-down polio," with almost total loss of shoulder and arm function but with some leg function, I can stand while being dressed and undressed. My ability to stand simplifies my dressing because the dresser can "drape" my body instead of pulling and tugging garments on while rolling me back and forth on a bed.

So there I was, standing, waiting for the pulling up of my underpants, the left leg of which, because of the brace on my left leg, tends to twist. When they were at my knees, I told Jeanne they were twisting; through gritted teeth she said, "Wait just a minute, Ellen. I'll fix them." She pulled them all the way up and then tried to straighten them, twisting cotton pants against cotton corset.

At that point, Harriott exclaimed, "The trouble is, Ellen, you want to be dressed perfectly." I shot back, "Is it asking too much to be dressed the way I dress?" and burst into tears.

I did a lot of bursting into tears back then. I don't now because I went into psychotherapy about that time to rid myself of some of the anger and frustration building up during those life changes. I spent hours weeping and wailing to my therapist about how I needed some control over my life, and he spent

hours helping me to get it. He watched me move from being a dependent daughter to being an independent woman in her late forties — now I laughingly describe myself as the most dependent Type A personality I know.

Another significant helper in that maturing process was Kay, the young woman whom I chose as my full-time physical caregiver in March 1980. I interviewed her in my campus office toward the end of my second week at Jeanne's house.

I had set up two tests. Since breaking my leg in 1973, I had used on campus the small glide-about chair which I maneuvered with my right leg, in control unless someone decided to "help" me by grasping the hand grips. Thus, as my first test, I would present my back to Kay. If she laid a hand on my chair as we moved to my office, she'd be out.

Next, after a little chit-chat, I would say I needed to go to the bathroom. Again presenting my back, I'd instruct her in the opening and shutting of doors and the positioning of herself in relationship to me — sometimes in front, sometimes behind. Once she, I, and my chair were inside the stall, I would stand up and move to the commode. Facing her, I'd tell her step-by-step how to unbutton the button, unzip the zipper, and pull down first my outer pants and then my underpants.

The second test, a direct result of my experiences with Jeanne, would occur when I had finished with the commode and stood facing her. I would say nothing, but wait for her to retrace the steps in arranging my clothes.

Having come to know Kay in the seventeen years we've lived together, I have often wondered how she knew not to touch me unless the process required it. And because she too likes to be in control, I find remarkable her not taking hold of my wheelchair. She passed my tests beautifully.

As important as these influences have been, without good, long-term medical care, I wouldn't be writing these words. I've had the same primary-care physician since 1977, a physician who expects his patients to communicate with him often and in detail. I never go into his office without a list of items to discuss and a printout of my current medications, including over-the-counter stuff. Before I saw him the first time, he asked that I write up my medical history. I opened by saying, "Both my life and, therefore, my health have been shaped by the fact I've been a polio quad since the age of four in 1937." I closed by saying, "As you may gather, I see a great deal of truth in John Milton's

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AGING POLIO SURVIVORS AND CHANGING VENTILATION NEEDS

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Case No. 1

Male, DOB 1939.

Dx: post-polio, quadriplegia, weakness in neck. Vital capacity: zero; vital capacity with GPB: 1.6L (1984).

- 1955: Polio. Months in iron lung, weaned to chest shell.
- 1956-1981: Day: pneumobelt (sitting) 12-14 hours; mouth intermittent positive pressure (MIPPV). Night: chest shell.
- 1981: Trial of poncho failed.
- 1981 to date: MIPPV with lipseal at night.
- 1987 to date: Cotton pledgets in nostrils to prevent night-time air leakage.

Discussion. Case No. 1 has used the pneumobelt for more than 40 years. It is possible to use the pneumobelt for a lifetime, but not if the abdomen is too obese. He had to give up the chest piece, because it no longer ventilated him adequately. After several years of using MIPPV at night, air started to leak from his nose. To prevent the leaks, he put cotton pledgets in his nose sealed with 3M paper tape.

Case No. 2

Female, DOB 1941.

Dx: post-polio, scoliosis. Vital capacity: 0.5L; vital capacity with GPB: 1.3L (1984).

- 1947: Polio. One month in iron lung.
- 1964-1966: MIPPV during day and evening.
- 1966-1981: MIPPV during night.
- 1981-1984: Covered face and mouthpiece with scarf.
- 1984: MIPPV with lipseal.
- 1996: Trial of nasal IPPV failed. Cotton pledgets in nostrils to prevent night-time air leakage.

Discussion. For almost 20 years, Case No. 2 used nothing, then she developed scoliosis which contributed to her need for ventilation. She began using MIPPV during the day when she felt tired, and when she was watching TV in the evenings. A few years later, she began using MIPPV during the night, and was adequately ventilated for 15 more years, until she noticed air leakage during the night. She tried to solve this by covering her face and mouthpiece with a scarf, but began having headaches during the night and upon awakening. A trial of nasal IPPV last year failed, because she had difficulty adjusting to the mask. Like Case No. 1, she finds cotton pledgets useful in sealing off the nose.

At Goldwater, we took a small (to be expanded) sample of eight post-polio ventilator users — all except one over 50 years of age — to track their changing ventilation needs. They all use IPPV, except for one who uses a pneumobelt around the clock (she sits up to sleep). Many use the old Maxivent (pressure-regulated) at the bedside because it is extremely reliable. Some have begun to use the volume ventilators, PLVs or LP10s. The In-exsufflator cough machine is used by several to prevent and control respiratory infections, and almost all of them agree that it is best to buy the one with the timing device, unless your caregiver is very experienced. It would be wise to rent the In-exsufflator for a week (call any of the Respironics/LIFECARE offices) in order to become familiar with it before the onset of a respiratory infection. Almost everybody has a manual resuscitator, but are unfamiliar with it. Everyone should take it with them when they go out, but should practice with it ahead of time.

The settings on the Maxivent cover a range and do not seem to relate to one's weight, but if you are over 150 lbs., pressures are 40-50 cm H₂O. This may seem high, but the pressure that you read on the machine is not the pressure you are getting in your lungs. It depends on the length of the hose between the machine and your mouth or your nose. The longer the hose the greater the drop of pressure — with a pressure of 40 on the machine, it may only be about 15 or 12 cm by the time it hits your mouth. Under 150 lbs., pressures can be 24-42 cm. A great deal depends on the compliance of your lungs.

With the volume ventilators, if one is under 110 lbs., the volume should be under 1000 ml of air. However, if weight is over 110 lbs., the volume is 1400-2400 ml of air, generally not more than 1700 ml. This allows for leaks. You need about 6L altogether per minute. The LP10 does have a flow-limiting device which allows it to be used as a pressure-regulated ventilator; which many ventilator users prefer. The PLV-100 can be used in the same way, but it is not quite as simple.

At night, most of the eight respiratory polio survivors are still using the Cascade humidifier with settings of 3 to 5. During the day, some of them use an in-line humidifier and some don't bother at all if they are using mouth intermittent positive pressure ventilation (MIPPV).

Only two in the sample are using the pneumobelt with pressures from 28-38 cm H₂O and higher if there is food in the stomach. Both are frog breathing more in order to speak efficiently and distinctly. The polio survivor who has been using the pneumobelt for forty years now finds he is frog breathing more than before; the pneumobelt isn't ventilating him as adequately. With the greater amount of frog breathing, he is also getting more gas in his stomach during the day.

Everybody in this group frog breathes, from ten minutes to a few hours daily when not using MIPPV. Others use it continuously in conjunction with MIPPV or the pneumobelt. Some use it to help produce a deep cough.

Weight is very important. Two female polio survivors have been able to keep their weight stable, but the weight gain varies from 15-70 lbs., and in one instance, more than 100 lbs. To lose weight, one female used a modified Weight Watchers diet. The other tried by hypnosis with the post-hypnotic suggestion to divide everything she eats by half. She has lost about 15 lbs.

Pulmonary function testing is usually performed annually. Vital capacity should be measured in both a sitting and supine position, because respiratory polio survivors may have a reasonable vital capacity sitting, but a very low one lying down, or vice versa. Pulse oximeters that clip on a finger are available for home use and a good way to monitor oxygen saturation. Oxygen desaturation due to mucus plugs or atelectasis (collapsed lung) or pneumonia which may be getting worse can be quickly assessed with a pulse oximeter. If it drops below 92%, it is time to call the doctor.

Most of the group take the flu vaccine every year and have had the pneumococcal vaccine once. The pneumococcal vaccine should last a lifetime, but if taken over ten years ago, one might decide to have it a second time, especially because of the increasing number of antibiotic-resistant bacteria. As always, ask the advice of a physician. Nutritional supplements are popular, as are multi-vitamins and minerals, the antioxidants such as Vitamin E, and the herbal medicines echinacea and pycnogel.

Aging polio survivors should be aware of possible changes in their ventilation needs. As you get older the chances of becoming unconscious are greater; there is always the possibility of stroke or heart attack. Are you better off with trach intermittent positive pressure ventilation (TIPPV) if you become unconscious? Probably yes, but if you carry the manual resuscitator and have an attendant with you, you can be ventilated just as well as you would with

TIPPV. Many people who are rehabilitated with a trach don't use a cuff anyway. If there is no cuff on it, and if you're unconscious, it doesn't work for ventilation — everything leaks out of your nose and mouth. The nose and mouth must be sealed off for effective TIPPV in an unconscious individual.. ❄

DEFINITIONS:

CHEST SHELL — a fiberglass shell fitted across the chest. To assist inhalation, negative pressure is created outside the chest wall when air is sucked from the shell through tubing attached to a ventilator.

GPB — glossopharyngeal breathing or "frog breathing" is a method of obtaining more air by gulping air into the lungs using the tongue and throat muscles.

INTERMITTENT POSITIVE PRESSURE VENTILATION (IPPV) — air is delivered into the lungs at a controlled amount of pressure or volume, either via mouth (with lipseal or mouthpiece to suck air from), via nose (with nasal or face mask), or via tracheostomy.

LIPSEAL — mouthpiece strapped to head to prevent air from leaking from the mouth.

PNEUMOBELT — a corset-type affair worn around the abdomen to assist expiration. It intermittently inflates, compressing the abdomen, and forcing air out of the lungs. Effective only when sitting or standing.

PONCHO — fabric garment, similar to body wrap, attached by tubing to ventilator. Same negative pressure principle as chest shell. Effective only in supine position.

VITAL CAPACITY — the maximum amount of air that can be exhaled after taking a deep breath.

AUGUSTA ALBA, MD, Director, Department of Rehabilitation Medicine, Goldwater Memorial Hospital, came from the field of neurology into rehabilitation during the 1950s polio epidemics. She was completing her residency in 1953 at Goldwater, then one of the regional polio respiratory centers. Dr. Alba says, "I fell in love with the place and have been there even since." She has attended every GINI conference on post-polio since 1981, and has lectured and authored many medical journal articles on the subject.

POST-POLIO BIBLIOGRAPHY

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The diagnostic criteria, both clinical and laboratory, for post-polio muscle dysfunction was first proposed by the participants of an European Neuromuscular Centre (ENMC) Workshop in Naarden, The Netherlands (1994). During the final session, the 16 participants recognized the need for a new term and diagnostic criteria primarily considering the neuromuscular symptoms in order to be able to compare different studies focusing on muscle problems.

A summary of the diagnostic criteria for post-polio muscle dysfunction, as presented by Borg, Borg, and Stålberg in the above citation follows:

1. History of paralytic polio: confirmed or not confirmed; partial or fairly complete functional recovery.
2. After a period of functional stability of at least 15 years development of new muscle dysfunction: muscle weakness, muscle atrophy, muscle pain, muscle fatigue.
3. Neurological examination compatible with prior polio-myelitis: lower motor neuron lesion, decreased or absent tendon reflexes, no sensory loss, neurophysiological and magnetic resonance imaging (MRI) and muscle biopsy examinations compatible with prior poliomyelitis.

Kristian Borg, MD, Department of Neurology, Karolinska Hospital, Stockholm, was appointed chairperson of an international consortium for research on post-polio muscle dysfunction. Other members include: Frank Lønnberg (Denmark); Andoni Urtizberea (France); Reinhard Dengler, Dieter Pongratz, Reinhardt Rüdell (Germany); Gisli Einarsson (Iceland); Barbara Ivanyi, Paul Oostvogel, Michael Rutgers, Marianne de Visser (The Netherlands); Jörgen Borg, Kristian Borg, Gunnar Grimby, Erik Stålberg, Anna Tollbäck (Sweden); and Alan E.H. Emery (U.K.), Research Director, ENMC.

The consortium will continue to meet focusing its attention on new therapies.

Gould, T. (1997). *A Summer Plague: Polio and Its Survivors*. New Haven: Yale University Press.

Originally published in 1994, *A Summer Plague: Polio and Its Survivors* is now available in paperback. This poignant book

is a comprehensive and compelling account of the twentieth-century experience of polio. Tony Gould, a distinguished British writer and polio survivor, recreates the widespread panic the disease created; follows the race for a cure; lets polio survivors tell their own stories; explores the effects of polio on Franklin Delano

Roosevelt; and examines the phenomenon of post-polio syndrome, which now affects many survivors. (Mr. Gould was a guest speaker at G.I.N.I.'s Seventh International Post-Polio and Independent Living Conference in May of this year.)

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Polio is a collection of essays written by nine people who experienced polio in several ways. Contributors include polio survivors; senior members of the Pan-American Health Organization involved in the monumental and successful task of eradicating acute poliomyelitis in the Western Hemisphere; scientists who dedicated their careers to viral research, including editor Frederick C. Robbins, who was a recipient of the 1954 Nobel Prize in Physiology, along with John Enders and Thomas Weller, for cultivating the poliovirus.

The other editor, Thomas M. Daniel, submitted "Polio and the Making of a Doctor," while Robert M. Eiben wrote "The Polio Experience and the Twilight of the Contagious Disease Hospitals."

Both gentlemen treated polio patients in Toomey Pavilion at City Hospital (now MetroHealth Medical Center) in Cleveland, Ohio. Toomey Pavilion was the twelfth of fifteen regional respiratory care and rehabilitation centers established in the 1950s. (Gini Laurie, founder of Gazette International Networking Institute, was a Red Cross volunteer at Toomey Pavilion and became editor of the center's newsletter in 1958. G.I.N.I. has been publishing and networking information since that time.)

INTERNATIONAL POLIO NETWORK

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POLIO NETWORK NEWS is an international newsletter for polio survivors, health professionals, and resource centers to exchange information, encourage research, and promote networking among the post-polio community.
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notion that 'The mind is its own place, and in itself can make a heaven of hell, and a hell of heaven.'"

I'm sure my doctor finds disconcerting that his patient never gets better, only worse. Through these years of change, however, he's been steadfast in his effort to help me function. He drew my attention to the computer in the early '80s when he sent me an article from the *Wall Street Journal* predicting the importance of computers to the physically limited. He encouraged me to move out onto the Internet to do my own medical research. And he always encourages me to interact with other doctors as I interact with him — asking questions, writing up notes as medical problems develop, following threads as they lead me to decisions I must make, always with his advice.

Now that I'm on the Internet, I have access to more medical information than I ever dreamed of — all without having to lift a book or turn a page. By striking a few keys, I can find a discussion of gallstones, which I have, or a medicine like Plendil, which I take. Information about searching the Internet is widely available: the February 1997 issue of *Consumer Reports* had an in-depth article about Internet sites dealing with medical matters and the July 1996 *Harvard Health Letter* had a Special Supplement containing references both on the Internet and in books for help in answering medical questions. Another of my favorite articles is "Don't Be a Wimp in the Doctor's Office" in the August 1996 *Harvard Health Letter*.

I'm lucky: I have responsive physicians and a strong support system. But my bottom line is that I often create my luck by keeping my eyes and ears open, asking question after question after question, and, above all, trying to first-guess everybody involved in my care — and that includes everybody I know. ❧

Moving???

Please send your old and new addresses to:

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e-mail: gini_intl@msn.com

NEW POST-POLIO SERVICES

ALBUQUERQUE

Saint Joseph Rehabilitation Hospital has begun a comprehensive post-polio service in Albuquerque, New Mexico, as of September, 1997, to provide assistance throughout the southwestern United States. Persons with a history of polio can receive a consultation, diagnosis, treatment, and follow-up by a team of physiatrists, physical therapists, psychologists, occupational therapists, speech and language therapists, and nutrition counselors. Saint Joseph has a fully-equipped gym, an activities-for-daily-living center, and a handicapped-accessible therapeutic pool.

Polio survivors may be referred through their primary-care physician, private healthcare physician, or a physiatrist. Self-payers may call directly. Callers will receive information, literature, and, if desired, a call back from a team member providing an opportunity to discuss individual symptoms before visiting the clinic. At the clinic, polio survivors will be referred to appropriate therapies, and a medical team will plan a treatment strategy. Follow-up visits will be made by a nurse case manager at 6- and 12-month intervals, or more frequently if needed. The new post-polio service hotline number is 505/727-4901.

LOUISVILLE

Frazier Rehabilitation Center in Louisville, Kentucky, has established a new interdisciplinary post-polio clinic. It is the result of the combined efforts of Judah L. Skolnick, pulmonologist at the Jewish Hospital Heart and Lung Institute; Frances Brown, Polio Survivors Organization; and Keven S. Hollars, RN, clinic coordinator at Frazier Rehabilitation (affiliated with The Jewish Hospital).

A questionnaire was developed to obtain general poliomyelitis history, new problems associated with the late effects of poliomyelitis, and survivors' input on services that would benefit them in a post-polio program. The results were used in developing the clinic program.

The purpose of Frazier's post-polio clinic is to help survivors manage lifestyle changes that maximize long-term health and wellness. Before attending the clinic, survivors are sent an assessment form to assist the clinic team in its two-day evaluation. Day One consists of evaluations by the physiatrist (a physician trained in physical medicine and rehabilitation), clinic coordinator, physical therapist, occupational therapist, and psychologist. Laboratory tests, X-rays, or EMGs are done as indicated by the physiatrist. On Day Two, following the team's recommendations, other consults are made by pulmonary rehabilitation specialists, dietitians, speech therapists, and orthotists. Polio survivors meet with the medical team, try suggested interventions, and receive any additional recommendations.

For more information concerning the clinic or for a copy of the questionnaire and its results, call 502/582-0542 or write to Keven S. Hollars, RN, Clinic Coordinator, Frazier Rehabilitation Center, 220 Abraham Flexner Way, Louisville, Kentucky 40202.

THE FRENCH POST-POLIO SUPPORT GROUP

HENRI CHARCOSSET, CATHERINE COUSERGUE, AND NICOLE RICHIER-JOUE

After rehabilitation, many young French polio survivors started voluntary groups and created associations, which later became cross-disability groups. Around 1980, at the beginning of studies about the late effects of polio, these groups reached only a small percentage of the polio population in France. Furthermore, they did not deal with medical issues. Many polio survivors had difficulty in getting information about current studies and wanted to be properly informed, so we organized a post-polio group in 1989.

I was born in 1936 and had a tetraplegic form of polio in 1953. I spent two years at the Hôpital de Garches near Paris in a 22-bed dormitory with polio patients of every social, cultural, and professional class ranging from 16 to 40 years of age. These associations contributed to my career choice. I became a researcher at the Centre National de la Recherche Scientifique (the French National Research Center) where I tested, analyzed, and studied coal.

The idea for this group came out of my previous life experiences. The French Post-Polio Support Group emphasizes a pragmatic approach to the late effects of polio, and its affect on our everyday lives, rather than a theoretic or idealistic approach.

Our group acknowledges that polio and its late effects are indeed a medical entity that should be a subject of research. There is no question of the relevance of this data. However, we also acknowledge that polio survivors have "experimentator status" from living with the late effects. Sometimes polio survivors with no medical background are more competent in understanding issues related to having had polio because of firsthand experience.

As a consequence of this "experimentator status," the relationship between a polio survivor and his or her medical team is almost the equivalent of the relationship between a technician and a researcher in an



Henri Charcosset was a research director at the Centre National de la Recherches Scientifiques (C.N.R.S.) and is now retired.

experimental laboratory. Both are regarded as competent and each respects the other.

We offer the opportunity for everyone to contribute to the group:

The French polio population is composed mostly of people living far from big cities or in medical or retirement homes. Due to their lack of mobility, and the workload of the medical staff, we decided to organize the work for the group from home or working place.

We continually translate information into French, and a database has been created by the Association d'Entraide des Polios et Handicapés — ADEP (Associ-ative Support Group for Polio and Handicapped People).

Due to the retirement of medical personnel that practiced at the time of the polio epidemics, the specialized medical follow-up of French post-polio survivors was not very well organized and somewhat lacking in efficiency: our initial work was to complete an exhaustive bibliographic analysis of the post-polio literature for the 1980-90 period and have it distributed among medical specialists. Thanks to a collaboration between Henri Charcosset and Catherine Cousergue, the French Post-Polio Support Group created a network of about 30 specialized medical departments in hospitals for the follow-up of post-polio patients through-out France.

We welcome retired professionals from the health services to join the group.

We also collaborate with other post-polio groups from around the world and have considered this activity of the utmost importance right from the start.

Our group information is published in *Le Pont Carré*, a cross-disability quarterly which is very well known in the medical world. A subscription to this magazine is equivalent to membership in the group, without being compulsory. *Le Pont Carré* is written by patients from Hôpital de Garches, which was one of the major treat-



Catherine Cousergue is a medical doctor in Pharmacology and editorial advisor.

ment centers at the time of the epidemics before polio vaccination became obligatory in France.

With the help of the A.P.F., L'Association des Paralysés de France (the French Association for Paralyzed People), we published a French version of the *Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors*, published by Gazette International Networking Institute, complete with our bibliographical analysis for the 1980-90 period. To date, we have distributed 3,500.

Since our group was formed, a medical survey, several medical theses, and other works of research have been completed under the supervision of Pr. J.P. Held, to whom Pr. O. Dizien succeeded, Dr. B. Biot, Pr. Eysette, and Pr. G. Serratrice. Written reports of this research are available in French only.

The medical and psychosocial survey among the French polio population was supported by the Société Française de Médecine et de Rééducation et Réadaptation — SOFMEER (the French Medical Society for Rehabilitation). Additionally, financing of post-polio research in France comes from the A.F.M., the Association Française contre les Myopathies (French Association against Myopathies) fundraising telethon.

Our group has no official status, but it nevertheless plays a central role in networking with *Le Point Carré* and with the French medical specialists, and in advocating for members of the group. Since our work is completely voluntary, each leader is given the responsibility to find and train another post-polio person to succeed him or her.

I succeeded Henri Charcosset in 1993 and my goal has been to continue the work while preserving what has been achieved previously.

Each year we translate and distribute between five to ten medical publications of post-polio experts among medical staffs and post-polio people; and continue to support research in France by Pr. J. Julien and colleagues (neurology), Pr. A. Delarque and colleagues (rehabilitation), and Dr. M. Bouffard-Vercelli and colleagues (physiotherapy), among others.

Our group's new activities include: acquiring phone lines for post-polio people; writing (in March 1995) and disseminating a booklet summarizing our activi-



Nicole Richier-Jouve is a social worker.

ties from 1989 to 1994; advertising our group in publications other than those about disability; developing a relationship with other European post-polio groups such as those in Switzerland and Belgium; and connecting with polio survivors in Portugal where there are no post-polio support groups.

Since the 30 specialized medical follow-up departments have been established, solutions to the problem of having to reduce activities, which is often necessary, seem to be available. We sense no real interest by post-polio people in developing friendships among themselves, since they have already developed personal relationships and friendships by the time the late effects appear.

Our work is important because the late effects of polio represent a very important chapter in the general theme of aging with a disability.

We have a problem in finding new members to replace the most active ones. There are several reasons rather than one for this phenomenon, but the main reason is common to every slowly progressive, chronic illness — survivors underestimate the need to take charge of their own specialized and associated medical problems.

In addition to Henri Charcosset, Catherine Cousergue, and Nicole Richier-Jouve, the work of the group is coordinated by a team of post-polio people: Denise Biehler (retired physiotherapist, who later became a social worker), Gisele Derouault (psychologist), and Ann Gautier (translator).

The French Post-Polio Support Group's team for 1997 is composed of the persons mentioned previously, as well as Michele Tachouet (in charge of general relations with the press), Nichole Trischler (the housing conditions issue), Marie Heraud (the polio problem in developing countries), and Marie-Pierre Servant (translations). New members are always welcomed.

Special thanks to Lynne Breakstone, Senior Lecturer of French, Washington University, Saint Louis, Missouri.

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NEW PPS SERVICES CONTINUED FROM PAGE 9

SAN DIEGO

The Post-Polio Achievement Center (PPAC), located in San Diego, California, is designed to assist people who had polio and are experiencing difficulty walking. Established to provide a comprehensive healthcare program for those experiencing symptoms of post-polio syndrome, the PPAC is a division of Southern California Orthotics and Prosthetics, Inc. (SCOPE).

Heading the PPAC is Loren Saxton, CPO, an orthotic professional for over 35 years, who had polio as a child and is currently experiencing post-polio symptoms. Saxton's first-hand experience is beneficial as he creates, fits, and adjusts advanced bracing techniques to improve the function of survivors.

The PPAC can provide a comprehensive evaluation, identify appropriate mobility aids, provide the latest in orthopedic technology, decrease pain and misalignments associated with post-polio problems, and maximize endurance for daily activities.

The staff includes American board-certified orthotists, physiatrists, physical therapists, massage therapists, occupational therapists, dietitians, and consultants knowledgeable about durable medical equipment and mobility and home modifications.

For information about the Post-Polio Achievement Center located at 7720 Cardinal Court, San Diego, California 92123, call 800/465-4627 or 619/292-0927 fax.

KANSAS CITY (Missouri)

A new post-polio group has formed in the Greater Kansas City (MO) area. The Northland Area Post-Polio Support Group was created to serve the northern area and plans to

meet every other month. For more information, contact Max Waterman, MD (816/781-4558) or Keith R. David, PhD (816/781-5435).

NEW YORK

Polio survivors in Manhattan are asked to send their name, address, and phone number to International Polio Network, if they are interested in connecting with another polio survivor to be part of the core of a new support group. ⇐

Calendar 1998

LIVING WITH DISABILITY: EXPLORING THE AGING PROCESS, FEBRUARY 6-7, Wyndham Emerald Plaza, San Diego, California. Contact: Ed Cantrell, Assistant Training Director, RRTC on Aging and Disability, 7601 East Imperial Highway, 800 West Annex, Downey, California 90242 (562/401-7402 or 562/401-7011 fax).



OPENING THE DOOR TO NEW KNOWLEDGE, FEBRUARY 14, Holiday Inn West, Ocala, Florida. Contact: Carolyn Raville, North Central Florida Post-Polio Support Group, 7180 SW 182nd Court, Dunnellon, Florida 34432 (352/489-1731).



NOTHING CAN STOP US NOW, MAY 1-3, Sheraton Perimeter Park South Hotel, Birmingham, Alabama. Contact: Wanda Merrill, 717 Rockhurst Drive, Birmingham, Alabama 35209-3170 (205/290-9477, 205/945-8541 fax, or comquate@aol.com).