

POLIO NETWORK NEWS

INTERNATIONAL POLIO NETWORK



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PAIN IN POST-POLIO SYNDROME

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(deceased)

Symptoms of post-polio syndrome include fatigue, new weakness, and pain in muscle and joints. Chronic pain is the second most prevalent symptom reported and frequently is the most difficult to treat. Improvement in the evaluation and treatment of pain can significantly improve comfort and restore function. The differential diagnosis is extensive, but many of the problems appear to be related to overuse of weak muscles along with abnormal joint and limb biomechanics.

To facilitate the diagnosis and treatment of pain, a classification that divides the pain syndromes into three classes has been developed: 1) *post-polio muscle pain*; 2) *overuse pain*; 3) *biomechanical pain*.

POST-POLIO MUSCLE PAIN occurs only in muscles affected by polio. It is described as either a deep or superficial aching pain, which many survivors say is similar to the muscle pain they experienced during their acute illness. Characterized by muscle cramps, fasciculations, or a crawling sensation, it typically occurs at night or the end of the day when one tries to relax. It is exacerbated by physical activity and stress, and cold temperatures.

OVERUSE PAIN includes injuries to soft tissue, muscle, tendons, bursa, and ligaments. Common examples are rotator cuff tendinitis, deltoid bursitis, and myofascial pain. Myofascial pain in post-polio is similar to that in others. It occurs most frequently in the muscle of the upper back and shoulders and is characterized by bands of taut muscles and discrete *trigger points* that elicit a *jump* response when palpated. These occur due to poor posture or improper body biomechanics.

Fibromyalgia (see box on page 2) with its associated symptoms is another cause of muscle pain that has been recognized by other investigators and has similar symptoms, but is distinctly different from post-polio muscle pain. The classic *tender points* are uncommon with post-polio muscle pain.

BIOMECHANICAL PAIN presents as a degenerative joint disease (DJD), low back pain, or pain from nerve compression syndromes. Weakness induced by polio affected muscles, as well as poor body mechanics, makes the joints more susceptible to the development of DJD. Survivors who walk develop degenerative joint disease in the lower extremities because years of ambulating on unstable joints and supporting tissue increase the chance of developing further pain and deformity. Those

who use wheelchairs or assistive devices such as canes, crutches, or walkers are prone to DJD, or overuse syndromes, in their upper extremities, especially the wrist and shoulders. The joint pains are only rarely accompanied by swelling and/or inflammation, but do demonstrate tenderness and abnormal range of motion. X-rays of painful, weight-bearing joints may show degenerative changes proportional with the amount of stress the joints have sustained.

Nerve compression syndromes, including carpal tunnel syndrome (CTS), ulnar mononeuropathy at the wrist or elbow, brachial plexopathy, and cervical or lumbosacral radiculopathy, are syndromes that can cause pain as well as neurological

deficits in the post-polio individual. Risk factors for the development of focal neuropathies of the median and ulnar nerves include use of an assistive device such as a cane, crutch, or wheelchair. These neuropathies can be detected on electrodiagnostic tests (EMG/NCS) before the individual has the characteristic symptoms of CTS.

The evaluation of post-polio individuals with pain requires careful investigation of all aspects of their pain. Among the questions asked are typical ones such as "What makes the pain better?" and "What makes it worse?" The way pain interferes with the survivors' ability to sleep and work is noted. Which treatments are helpful and by whom they are given is also documented.

*"Altering the pace
and intensity of
discretionary activities
and learning new ways
to gain more control
over when and how
activities are performed
is essential."*

Pain management in post-polio is based on a few basic principles, supplemented by class-specific recommendations. These basic principles include efforts to:

- 1) improve abnormal body mechanics;
- 2) correct and minimize postural and gait deviations mechanically;
- 3) relieve or support weakened muscles and joints;
- 4) promote lifestyle modifications;
- 5) decrease the abnormally high work load of muscles relative to their limited capacity.

TREATMENT FOR POST-POLIO MUSCLE PAIN includes decreasing activity throughout the day, applying heat, and stretching. Stretching has a role in maintaining the extensibility of muscle and connective tissue; however, it must be performed judiciously because there are situations in which a polio survivor may derive greater functional benefit and be safer with tighter tendons and reduced joint range of motion.

A variety of medications are used to treat post-polio muscle pain, but the most common ones — such as nonsteroidal anti-inflammatories (NSAIDs), Tylenol, benzodiazepams, and narcotics — are of little use. The use of tricyclic antidepressants (TCAs), especially amitriptyline, can help with pain and also with fatigue.

TREATMENT FOR OVERUSE PAIN includes modification of extremity use, followed by modalities such as ice, heat or ultrasound, transcutaneous electrical nerve stimulation (TENS), and occasionally NSAID medications. Treatment for myofascial pain consists of myofascial release techniques, including spray and stretch and trigger-point injections. Often rest is not possible since many rely on upper extremities for both locomotion and self care. In rare cases, steroid injections or surgery may be needed.

TREATMENT FOR BIOMECHANICAL PAIN includes posture and back-care education and decreased weight bearing through use of assistive devices such as braces, crutches, wheelchairs, and scooters. Abnormal biomechanics can often be modified with fairly simple and practical interventions such as cervical pillows, lumbar rolls, glottal pads, dorsal-lumbar corsets, and heel lifts. These pains are usually improved by conservative measures aimed at reducing mechanical stress — pacing activities, supporting weakened muscles, stabilizing abnormal joint movements, and improving biomechanics of the body during common daily activities. Anti-inflammatory agents are used sparingly, and then only in low doses to supplement conservative measures. In particular, efforts should be directed at improving routine daily activities such as sitting, standing, walking, and sleeping, as well as any repetitious activities at

DIAGNOSTIC CRITERIA FIBROMYALGIA SYNDROME (FMS)

(according to the 1990 American College of Rheumatology)

To meet the criteria, patients must have:

- Widespread pain in all four quadrants of their body for a minimum of three months
- At least 11 of the 18 specified tender points

Although the above criteria focuses on tender point count, a consensus of 35 FMS experts have recently determined that a person does not need to have the required 11 tender points to be diagnosed and treated for FMS. This criteria was created for research purposes and many people may still have FMS with less than 11 of the required tender points as long as they have widespread pain and many of the common symptoms associated with FMS. Commonly associated symptoms include:

- fatigue
- sleep disorder (or sleep that is unrefreshing)
- jaw pain (TMJ dysfunction)
- post-exertion malaise and muscle pain
- numbness and tingling sensations
- skin sensitivities
- irritable bowel
- chronic headaches (tension-type or migraines)
- cognitive or memory impairment
- morning stiffness
- menstrual cramping and PMS
- dizziness or impaired coordination

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work. Weight bearing with the wrist hyperextended and radically deviated should be avoided.

For those with carpal tunnel syndrome who must use a cane or crutch, an Ortho-ease or *pistol grip* is prescribed to place the wrist in a more neutral position and spread out the weight-bearing surface on the palm. Providing adequate support for weakened muscles and unstable joints can often be a difficult challenge; how-

ever, the basic orthotic principles are similar to those used in the management of other neuromuscular diseases. For individuals with low-back pain, lumbosacral corsets, a shoe lift, or pelvic lift can help improve biomechanics. For genu recurvatum (back knee) or genu valgus (knock knee) due to quadriceps weakness or ligament instability, a long-leg brace (KAFO — knee, ankle, foot, orthosis) with a free ankle and an extension stop at the knee is used. Polio survivors with dorsiflexion weakness or ankle instability can benefit from an athletic ankle splint, high-top shoes, or a short leg brace (AFO — ankle, foot, orthosis).

Many individuals need an orthosis that combines strength and lightness. The new plastics and lightweight metals can often be used alone or in combination. Frequently, survivors prefer to repair and use their old braces rather than start over with new ones. Others may resist using any kind of brace for cosmetic and psychological reasons. Orthotics are recommended for the following indications: 1) to improve safety by reducing the risk of falls; 2) to reduce pain; 3) to decrease fatigue by improving gait speed and symmetry.

Pain can be reduced by altering biomechanics and by changing to a lifestyle that reduces physical activity. These strategies may be difficult to accomplish, however, because they often require developing behaviors unlike the old, familiar ones. Altering the pace and intensity of discretionary activities and learning new ways to gain more control over when and how activities are performed is essential. Restoration of function as well as relief of pain can be accomplished by an interdisciplinary team that includes the polio survivor, physical therapist, occupational therapist, psychologist, rehabilitation engineer, and physician. ←

ANNE CARRINGTON GAWNE, MD received her medical training at the Uniformed Services University in Bethesda, Maryland, and did her residency at the National Rehabilitation Hospital in Washington, DC.

Before moving to Spain Rehabilitation Center at the University of Alabama in Birmingham, Dr. Gawne treated polio survivors at National Rehabilitation Hospital for nine years. She co-authored *Post-Polio Syndrome: Pathophysiology and Clinical Management* with Lauro S. Halstead, MD, National Rehabilitation Hospital, which was published in *Critical Reviews in Physical Medicine and Rehabilitation*, Vol. 7, Issue 2, pages 147-188.

To receive a copy of Dr. Gawne's Post-Polio Pain Evaluation Questionnaire, send a self-addressed stamped envelope to her at Spain Rehabilitation Center, 1717 Sixth Avenue South, Birmingham, Alabama 35209.

SKILLS HELPFUL IN MANAGING PAIN

FROM THE AMERICAN CHRONIC PAIN ASSOCIATION

We do not dwell on physical symptoms of pain. Instead we focus on becoming a person rather than being a patient.

We recognize and talk freely about our feelings about pain and its control over our lives. We do not make judgments.

We use relaxation audiotapes to help ease the tension that increases pain.

We demonstrate mild stretching exercises and encourage you to do them daily, if your doctor approves.

We set realistic goals which are evaluated weekly. This helps members to see that their desires can be reached, one step at a time.

We become more assertive by recognizing our basic rights, including the right to make mistakes, the right to say no, and the right to ask questions.

The American Chronic Pain Association (ACPA) is an international non-profit, self-help organization that offers educational materials and peer support groups to help individuals live fuller lives in spite of chronic pain. To learn more about managing chronic pain (pain that lasts six months or longer) or to locate an ACPA group near you, contact the national office at 916/632-0922; 916/632-3208 FAX; ACPA@pacbell.net; write to the ACPA at P.O. Box 850, Rocklin, California 95677.

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MYOFASCIAL RELEASE: PERSPECTIVE OF AN INFORMED CONSUMER

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As the recipient of over 50 myofascial release treatments for my polio-related symptoms administered by Steven Moreau, MS, PT, I want to discuss the topic from the perspective of an informed consumer. I have paraphrased and quoted from materials prepared by Moreau.

OVERVIEW OF STRUCTURE AND FUNCTION OF FASCIA

Someone has said that if all tissues except fascia were removed from the body, our external appearance would remain relatively unchanged. This is because fascia, a three-dimensional network of connective tissue, extends without interruption from head to toe. It encircles, separates, connects, supports, communicates, and remembers. In general, fascia fibers are arranged longitudinally, although there are four major extensions of transverse fibers. Fascia plays a role in many areas of interest to polio survivors, including postural symmetry and balance (static and dynamic), support and shock absorption, cellular respiration, and metabolism. It is intricately involved with the maintenance of health at the system and cellular levels and influences immune function (Travell, 1983).

There are three layers of fascia: superficial, deep, and subserous. Superficial fascia, located just below the skin, surrounds structures found near to the surface in our bodies, including capillaries and nerves (including pain receptors). Deep fascia surrounds and separates all muscles and internal organs. Subserous fascia covers internal organs including the brain and spinal cord.

Fascia can be injured in a number of ways, including by physical and emotional trauma and long-term overuse. When fascia is injured, it becomes restricted; the restriction then spreads like a pull in loosely woven fabric, forcing the body out of alignment and into postures and ways of moving that are inefficient, energy

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consuming, and fatiguing (Becker & Seldon, 1985). Further possibilities of increasing imbalance include muscle spasm, pain, and increased potential for degenerative changes.

CHANGES IN FASCIA RELATED TO POLIO AND POST-POLIO SYNDROME

Moreau provides us with a hypothetical example of how fascial changes could affect a person who has had polio. A polio survivor is fatigued. In response to this fatigue, movement creates asymmetry. The fascia provide support by tightening, causing more asymmetry. Muscle spasms occur as a protective reaction, compressing pain receptors in muscle and fascia in the process. The muscle spasms increase the pain and asymmetry. Fascial restrictions begin to spread affecting other areas of the body, increasing the stress on joints. If the fascia is not treated, chronic pain and degenerative changes may begin.

MYOFASCIAL RELEASE TREATMENTS

Myofascial release is a treatment for restrictions in fascia. To restore the body's natural equilibrium, the therapist gently applies a tractioning or compressive force with his/her hands to any part of the body that is out of balance. The changes in fascia resulting from such treatment include lengthening elastic components, increasing mobility of tissue layers, increasing fascial tissue glide, and decreasing abnormal proprioceptor (movement and body position) activity. Sensations reported by people receiving myofascial release include warmth, tingling, increased or decreased pain, emotional changes, and profound relaxation. My treatments have been restful and pleasant, with symptom relief either immediately or within an hour of treatment. Apparent long-term changes include increased range of motion, decreased frequency and duration of muscle spasms, and increased endurance. ◀

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THERAPEUTIC TOUCH: A HOLISTIC NURSING PRACTICE

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In 1985, when I was a graduate student in nursing at New York University, I had just begun to learn about post-polio syndrome and discovered that I was experiencing some of the symptoms. That same year, I enrolled in a master's level course called Therapeutic Touch (TT), taught by Dolores Krieger, RN, PhD, who had developed the technique in 1972. The word "synchronicity" seems to describe the "coincidence" of my learning at the same time about post-polio syndrome and TT, a treatment I was to find helpful in dealing with my symptoms.

Before I share my personal story, here is some background about TT, described by Krieger as a contemporary interpretation of several ancient healing practices, and defined as an energy field interaction. Although I had been in nursing for a long time, this concept was new to me; later I found a theoretical place for TT in nursing in the work of Florence Nightingale who believed that the work of nurses is to create an environment that supports the patient's own healing. She advocated for fresh air and clean water, good nutrition, good hygiene — which included putting only one patient in each bed, and caring, exemplified by her lamplight visits to say goodnight to her patients. In 1970, Martha Rogers, RN, ScD, Dean of the Division of Nursing at New York University, described human beings as energy fields.

Viewing energy exchange as a natural process led to Krieger's discovery that we all have the natural potential for purposeful energy exchange and that this potential can be used therapeutically by one individual for the well-being of another. As Krieger took this idea from theory to practice, she drew from the ancient practice of laying on of hands, the field theory of contemporary physics, and Eastern healing traditions based on a concept of energy called *prana*, *chi*, or *ki*. TT shares the underlying philosophy of other practices such as acupuncture and yoga that each of us has an intrinsic ability for self-healing.

Working with Dora Kunz, Dolores Krieger developed a systematic protocol for helping patients to relax, have less pain, and support their own healing process. For Therapeutic Touch to be effective, the person practicing TT, referred to as the healer, must feel compassion and the intent to heal. In treating with TT, the practitioner uses her/his hands to direct and modulate energy on behalf of another to help pattern his/her energy toward a healthier flow. Krieger's work represents not only the

art of nursing: the heart and hands, but the science of nursing: the intellect that synthesizes. It is nursing intellect that has led us away from a belief that the body and the mind are two separate parts of a human being, and to see that people are different from the sum of their parts.

TT is called complementary because although it can be used alone, it is intended to interface with, rather than replace, other treatment modalities. From the perspective of the practitioner, the process of TT can be described in four steps:

"I observed that my healing was taking place on different levels, but always at a gentle pace that felt right for me."

CENTERING: The practitioner quiets his/her mind, in a process called centering. During this step, the nurse enters a meditative state of awareness, tuning out the "busyness" of the immediate surroundings and becoming open to input from the patient.

ASSESSING: Attuned to the patient, the nurse "listens" passively with his/her hands, scanning the body a few inches above the skin. Assessment is based on the principle of symmetry; areas of difference, also called imbalance, are noted.

CLEARING (also called unruffling): This process, which involves smoothing out energy, is typically relaxing and soothing.

TREATING: Imbalances present after clearing are treated by sending energy through the patient, knowing that we are integrated and whole. Energy is sent to areas of deficit and moved through areas where it is not flowing freely. Pain-related energy is patterned into a calmer, more balanced flow.

While receiving a TT treatment, the healee is typically fully clothed, seated sideways on a straight chair. People may be treated in hospital beds or in their favorite chairs. The person being treated with TT can be alert or asleep, involved or detached, and can believe or not believe that it will make a difference. A treatment is not timed by the clock, but usually lasts 15 minutes or less. Allowing time for both healer and healee to remain relaxed immediately after the treatment is helpful but not required.

Typically, the patient experiences benefits in three ways: relaxation, lessened pain, and accelerated healing. TT has been researched for 25 years, and these benefits are

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SPOTLIGHT ON IRELAND

JOAN BRADLEY, DUBLIN, IRELAND

OUR PAST

Polio raged in Ireland from the 1940s to the late 1960s, declining sharply with the advent of vaccine and leaving a trail of skinny limbs, tilted spines, and dropped feet. The main epidemics occurred in the cities of Dublin and Cork, but the virus struck here and there all over the country. At first, the little patients (yes, most of them were children) were not isolated, but this changed as the virus spread.

With the disability came that deep, strong spirit to survive, to recover lost ground, to reach for the sky! Some did not survive and some of those who did struggled for years to gain independence and the highest degree of normality possible. At first, treatment was hot packs, physiotherapy, hydrotherapy, and the hated callipers and exercises. Although some later threw away their crutches, sticks, callipers, and such like, others never managed without a respirator for at least part of the day. There are still two such individuals at Cherry Orchard Hospital in Dublin, one of whom alternates between home and hospital.

Some children were in hospitals a long way from their homes, living and going to school there. When eventually reunited with their families, they were strangers, not always welcomed by their brothers and sisters. There were few rehabilitation units and some moved on to the industrial schools, which also acted as correction centers for delinquents, where the living was often rough. Others were cared for by dedicated, self-sacrificing parents, and the latter may experience a great sorrow when their parents die, feeling that they owe a debt that will never be paid.

Many recovered and, for the most part, gained employment and melted into the population; in this the Polio Fellowship of Ireland founded by Captain Talbot played a part. The Fellowship was founded in 1952 to help those who were subject to the disease, and it concentrated on rehabilitation and training in skills suited to the ability of those who attended. As time went on, the need for such training was less for polio survivors, and those with other disabilities are now helped by the Fellowship. Polio thankfully began to take a second place, and eventually most people forgot about it.

Even those who still carried the marks of it tried to forget and were successful to some extent until the arrival of new symptoms. Although survivors knew something

was wrong and began to seek advice from medical professionals, they were sent from one to another and got little satisfaction. The professionals tended to indicate that it was just "in the mind." A few learned about post-polio syndrome, or the late effects of polio, from international literature, such as *Accent on Living* and *Polio Network News*.

OUR RESPONSE

Ireland's only Post-Polio Support Group was formed in Dublin in 1993 after two polios, having obtained information from abroad and seeing the struggle and distress of their fellow polios, decided to do something about it. Finding a wide gap in information about the late effects of polio, they set out to rectify the matter by supplying information to both polios and medical people.

A neurological clinic at Beaumont Hospital in Dublin now specializes in post-polio syndrome and other



Joan Bradley (in light blouse) and members of the Post-Polio Support Group.

problems. Although the occasional survivor may be diagnosed elsewhere, those needing special assessment have to travel to Dublin where they are referred for any investigations that Dr. Orla Hardiman thinks necessary, including orthotic services, rehabilitation, respiratory investigation, orthopaedic or neurological surgery, rheumatology or psychological services. To have the Beaumont Hospital available is a success in which the Post-Polio Support Group played a small part, as it did in the 1994 conference when Marinos Dalakas, MD, an internationally recognized expert in post-polio, came from National Institute of Neurological Disorders and Stroke, Bethesda, Maryland, to speak to survivors who traveled from all over the country to hear him.

The number of polios still alive in Ireland is not known, but well-based estimates suggest that there may be about 9,300 still living and about 4,200 of these may experience post-polio syndrome over the next 20 years. There may also be some polios who have not yet heard of our support group. Although those experiencing the late effects of polio have the same needs as polios the world over, the damp climate in Ireland adds to the discomfort of those who suffer painful muscles and joints — these people often know when a change in the weather is coming and are adept at forecasting it. (Sometimes we think our national forecasters could do with our help!)

The Post-Polio Support Group is much involved in bringing the new situation before the health services and the general population. This involves lobbying government, seeking some financial help for those who cannot take on the new financial burden. Ireland's national health service covers those who are unemployed but gives only partial cover to those employed, who often have to bear part or the whole of their own

medical expenses, particularly for orthotic devices and callipers. Private health cover is available but expensive.

OUR CHALLENGE

The biggest challenge for us with post-polio in Ireland today is to overcome the remaining general ignorance of our condition, to forget how we got over our disability the first time, to learn to accept a new approach, and to give our bodies a little TLC (tender loving care), for a change. (I've tried it and it is wonderful!)

We in the Post-Polio Support Group believe that polios, who have made such a valuable contribution to the economic and social life of Ireland, should have the knowledge and the means to live the rest of our lives with dignity. ←

Joan Bradley, Post-Polio Support Group, Flat 2 C, Iveagh Trust, Kevin Street, Dublin 8. Ireland, (353) 01 454 9237.

POLIO AND POST-POLIO SYNDROME IN NEW ZEALAND

DENIS HOGAN, CHRISTCHURCH, NEW ZEALAND

New Zealand is a small, South Pacific country surrounded by thousands of miles of ocean. The indigenous Polynesian people, the Maori, settled here around 1000 A.D. European whalers and missionaries began to arrive in the early 19th century, leading to the country's being annexed by Britain as a colony in 1840. With the considerable emigration from Britain, the country steadily developed from a rough, frontier society to a trading society based on farming and mining.

Some suggest that the rise in the worldwide incidence of polio in the early part of the 20th century correlated well with the sharp decrease in gastrointestinal infective diseases such as typhoid and cholera. Advances in public health engineering led to the separate piping and treatment of sewage and drinking water, thus breaking the chain of infection and dramatically reducing the rate of gastrointestinal disease. The consequence, though, was that "natural" immunity to the polio virus was lost and the incidence of polio began to rise steadily in developing societies. New Zealand was no exception. Polio has been well described as a disease of civilization.

The first reports of poliomyelitis appeared in 1880. The first major outbreak occurred in 1914 in the southern of the two main islands comprising New Zealand. This outbreak led to polio being gazetted as a notifiable

disease. The first major country-wide epidemic occurred in 1916, the year of the infamous New York epidemic. Although it is not easy to see the connection between New Zealand and New York, some 10,000 miles distant, perhaps maritime trading was a factor.

Between 1914 and 1961, approximately 10,000 cases of polio occurred in New Zealand. When these are plotted against time (See Graph 1 on page 9), a pattern of major epidemics at 10-11 year intervals clearly emerges. This pattern is probably a general one, but I am not aware of any other country showing the dramatic 10 yearly peaks of polio cases. I am interested in hearing of the experience of other countries. New Zealand's isolation and its comparatively late development as an industrial society may be contributing factors to this distinctive pattern.

This pattern continued through the 1950s when polio infection in New Zealand began to assume the characteristics seen in North America, with annual summer outbreaks. The arrival of the Salk and Sabin vaccines halted further polio epidemics.

New Zealand statistics also show the steadily increasing average age at the time of infection. Polio was originally known in New Zealand, and I assume elsewhere, as "infantile paralysis" because of the large preponderance of very young people affected. In the 1916 epidemic, nearly 60% of those affected were 0-4 years of age. By 1955-56, this figure had dropped to about 15%.

Another interesting factor in New Zealand is the low rate of infection among the Maori race, which was largely country-based until the 1950s when a large

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migration to the cities occurred. This move coincided with the introduction of the vaccines and the elimination of polio. Again, I am interested in learning the experience of other countries. For instance, was there a marked difference in the rate of infection between European and African-American and indigenous peoples of the USA?



Denis Hogan

By 1961, virtually full immunization against polio had been achieved: there were no more cases of acute polio in New Zealand. Medical students were no longer taught about polio, which joined the ranks of defeated diseases. As elsewhere, polio survivors soldiered on and became hard-working and successful members of

society. They also began to experience the disturbing effects that eventually came to be known as post-polio syndrome, and found no understanding of their problems. Some New Zealand polios became aware of developments in the USA and two attended the Fourth International Polio and Independent Living Conference in St. Louis, Missouri in 1987. Following their report, Phillipa Morrison, later to become Patron of the New Zealand Society, set out to draw up a register of New Zealand polios and to convene a national conference, which was held in Napier in 1989. At this conference a constitution was adopted for the Post-Polio Support Society New Zealand, which was incorporated in 1990.

Because New Zealand's population is scattered through many small towns and cities, the Society has developed as a network of 25 locally organized and largely autonomous branches. These vary in size from only 12 members to 230 in the metropolis of Auckland (population 1,000,000). These 25 branches are coordinated by a Board of Management of ten members elected at the Annual General Meeting (AGM). The Board meets in person prior to the AGM; during the year, it meets by telephone conference because the high cost of travelling precludes bringing the widely-scattered members together. This system has proved to be an efficient way of conducting the Society's business.

The Society is very much a volunteer society — it has no paid staff. Communication with members is maintained first by the branches and second, and very importantly, through the quarterly national newsletter, which is distributed with the aid of a central national computerized address system on the Editor's personal computer. Financing is covered by a \$10 p.a. annual subscription and by donations. For the last two years, the Society has received a small grant from the New Zealand Lottery Board that distributes profits from the national lottery. This grant has enabled the Society to maintain a substantial newsletter, to build up a good library of information, and to begin to develop other services to members.

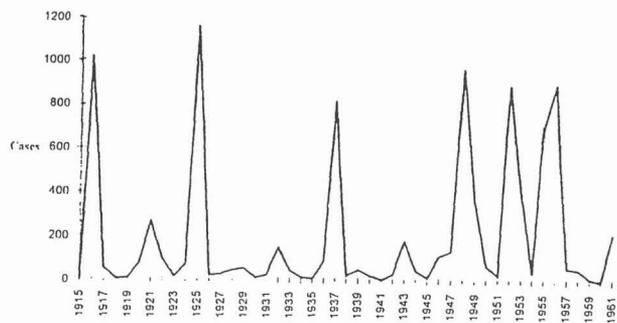
The aims of the Society are to provide support for those who have had polio: In particular, 1) to collect and distribute information enabling them to understand and moderate the changes occurring in their conditions; 2) to inform medical practitioners of the reality of post-polio syndrome and help update them on advances in research and treatment; and 3) to work towards the establishment of assessment and treatment clinics for polio survivors and at least one center of excellence in New Zealand for the study and treatment of post-polio syndrome.

The Society has organized successful national conferences in Napier (1989), Christchurch (1991), and Auckland (1994). We have made good progress with our first two aims, but the establishment of a specialist clinic appears to be still some way into the future.

From small beginnings in 1989, the New Zealand Society has grown to an active organization of around 1200 members. A survey conducted in 1992 revealed that probably somewhere between three- and five-thousand polio survivors live in New Zealand, so we have some way to go in contacting all of them and offering assistance.

New Zealand has over recent years been through quite dramatic economic and political restructuring that has

GRAPH 1:
CASES OF POLIOMYELITIS, 1915-1961



Source: F.S. Maclead, *Challenge for Health*, p. 319
Graph by Tim Hogan

led to significant changes in the health system. For the disabled, there have been two significant changes. First, all assistance to the disabled is now channelled through the health system instead of partly through health and partly through social welfare. Second, assistance is now negotiated on an individual basis using a "needs assessment" audit carried out by qualified assessors. This system has the potential to provide more and better assistance to the disabled and to use funding more efficiently, and we do see some improvement in some areas. However, as always, the monitoring mechanisms tend to be clumsy and overly bureaucratic.

Through this system of individual assessment though, even with a capped (and ring-fenced) budget, many disabled people have received help with wheelchairs, home alteration, domestic help, etc. The guiding

principle is to provide assistance to keep individuals independent, a principal that we strongly support. Although progress has been made, it is fair to say that the authorities underestimated the pent-up demand and that the capped budget is causing frustrations.

Polio survivors are the new boys on the block and getting the system to recognize their special needs, particularly the need for a specialist clinic, has so far proved impossible. However, much has been accomplished in a few years. Work continues and we are ever hopeful of achieving that major breakthrough.

Denis Hogan, President, Post-Polio Support Society, New Zealand, Inc., 11 Wyn Street, Christchurch 2, New Zealand, (64) 03-338 9552 phone/FAX.

THERAPEUTIC TOUCH CONTINUED FROM PAGE 5

supported by a number of studies. Over 150 controlled studies of healing have been published, with significant effects demonstrated in more than half. No harmful side effects have been reported or demonstrated (Benor, 1994).

Any healthy person with strong motivation to help others can learn TT. An estimated 30,000 or more people, most of them nurses, practice TT in the United States; others practice in other countries, including Canada, England, Australia, and Russia. Presently, although there is no certification specifically for TT, many experienced nurse practitioners are members of the Nurse Healers Professional Associates. TT treatments are covered as pain management by some third party payors and provided by some visiting-nurse agencies. Requests for nurses to provide TT in hospitals, clinics, and home visits are increasing.

Now I want to describe how I have experienced Therapeutic Touch as a polio survivor. Since 1986, I have been treated annually by Dora Kunz. Additionally, when I was experiencing an acute episode of right shoulder pain and loss of function, I was treated weekly for a semester by Dolores Krieger. When I fractured that same shoulder in the winter of 1992, I was treated by friends and TT students. I believe that TT is helpful to me physically, emotionally, and spiritually.

The first time that I was treated by Dora Kunz, I was tense and anxious, not knowing what to expect. She stood behind me, gently fluttering and sweeping her hands over my neck and shoulders, and down my spine. I responded to Dora's presence by relaxing, feeling warm and safe, and letting go of my anxiety. The third time that she treated me, she spent more time sending energy through the right-hip area, then said, "Now you have some energy going through that hip into your leg." I didn't understand what that meant, but

it sounded encouraging. The next day, I not only found my hip less tight, but I also found myself feeling the loss of someone close to me who had died that year and feeling thankful that he had been briefly in my life as I gently let go. I observed that my healing was taking place on different levels, but always at a gentle pace that felt right for me.

As I continued with TT, I found myself seeing some things in new ways. I experienced a sudden insight of how long I had disliked the way my body looked and had been impatient with its pains and weaknesses. I discovered myself thanking my body for not remaining paralyzed — for working hard for so many years, supporting me in becoming a nurse, a wife, and a mother. I vowed to be kinder and more supportive, realizing that my body and I are one and that I cannot live apart from my physical self.

Looking back on the years since I was introduced to Therapeutic Touch, I see that I am on a journey, involved in a healing process. I like knowing that I am part of the process — being "worked with" rather than "worked on" or "done to." I am more open to new ways of treatment, and optimistic about the possibilities for making the most of what I have. I don't know if my nerves and muscles have improved, but I have not become less able, and I believe that I have become more healthy in the fullest sense. ◀

REFERENCES:

- Benor, D.J. (1994). Healers and a changing medical paradigm. *Cooperative Connection*, 15(1), 1, 3-4.
- Straneva, J. (1994). Office of alternative medicine awards 30 grants. *Cooperative Connection*, 15(1), 7.

RESOURCES:

- Nurse Healers — Professional Associates, Inc., 1211 Locust Street, Philadelphia, Pennsylvania 19107, 215/545-8079.
- Krieger, D. (1993). *Accepting your power to heal*. Santa Fe: Bear & Company.

Readers Write

I receive *I.V.U.N. News* because I use a ventilator due to idiopathic scoliosis. I also subscribe to *Polio Network News*. In September I was involved in a motor car accident in which I injured my back. Because of the whiplash action of the collision, some of the cervical and thoracic vertebra collapsed inwards and bore down on the sternum, the point of which is now approximately 1 cm. closer to the spinal column than before. As a result, my chest cavity is reduced by approximately 20% and my vital capacity reduced from 500 cc to 360 cc. Whereas previously I only slept with the ventilator, I now only have seven to eight hours of ventilator-free time per day in periods of one hour at a time. If I stay off longer, I become desaturated. Although the physician will agree to it, the orthopedic surgeon does not think an operation is viable, as I could be totally ventilator-dependent after an operation. I was given physiotherapy exercises to do to strengthen my diaphragm and chest muscles but this has not brought about any improvement. I realize the details are very cursory, but others may have suggestions, precautions, etc. ...

ANNELIE, SOUTH AFRICA

Send your comments addressed to Annelie, at the International Polio Network address.

I wear two different sizes of shoes - size 4-1/2 or 5 on my left and size 8 on my right. I have many pairs of the opposites on hand and wondered if any readers might be interested in them. Most are SAS loafers and some are low-heel dress shoes.

RETHA GUIER, BOX 664,
CASCADE, COLORADO 80809

I usually have problems swimming in public pools because the water is too cold. I recently found swimwear which works for me. Contact Water Wear, Inc., 1 Riverview Mill, P.O. Box 687, Wilton, New Hampshire 03086-0687, 800/321-7848.

JANE, SOUTH CAROLINA

Does anyone have an operating manual for the Emerson rocking bed which they are willing to photocopy?

(Send to the International Polio Network address.)

Would you please publish the complete address for the National Neurological Research Specimen Bank? Contact Iris Rosario, RN, MA, National Neurological Research Specimen Bank, W.L.A. VA Medical Center, Building 212, Room 16, 11301 Willshire Boulevard, Los Angeles, California 90073 (310/268-3536).

Educating Others ...

✿ I'm sure that you get many request for information from people doing research on polio, but I wanted you to know how much I appreciated your response to me. My mom called on my behalf, explaining to you that I was doing a History Day project on polio and needed information. Your response was overwhelming. Not only did you send a multitude of brochures, pamphlets on current post-polio research, but books as well! I could not believe it. Thank you so very much for your response and your interest. I am a sophomore in high school, so my project was considered a "Senior Project." I received a 4th place ribbon for my paper in the Senior Division. I was pleased, as the competition was really tough this year.

KEVIN JACK, WILLITS, CALIFORNIA

✿ Polio survivor and author of children's books, Peg Kehret is also helping to educate our children. She has written *Small Steps: The Year I Got Polio*. An excerpt of her book, written for Grades 3-8, follows.

CHAPTER 4: "YOU CAN'T BURN MY BEAR!"

The next day I swallowed orange juice and broth. Soon I could eat small amounts of soft food such as oatmeal, tapioca pudding, and Jello. My chart still said NO MILK, but any time I asked for a milkshake, I got one.

Within days, I could swallow naturally, without thinking about it, and nothing I drank came back through my nose.

The deep, aching pain went away, and the muscle spasms stopped. It was easier to get my breath, too. The doctors decided to take me out of the oxygen tent for awhile, to see how long I could breathe on my own. My favorite doctor, a young blonde intern named Dr. Bevis, pulled back the plastic tent. I could see around me without everything looking foggy.

Someone turned the crank at the foot of my bed, and the upper half of the bed raised up, putting me in a semi-sitting position. The change felt wonderful.

"Breathe easy," Dr. Bevis said. "Don't take great gulps of air. Relax. Pretend you're going to sleep."

I closed my eyes. Because my chest muscles were so weak, my stomach, rather than my diaphragm, rose and fell as I inhaled and exhaled. Each time my lungs filled with air, my brain filled with excitement. I could breathe without the oxygen tent!

"You're doing great," Dr. Bevis said. "Let's try it on your own. We'll keep the oxygen tent here, in case you need it."

I opened my eyes and grinned at him. "I won't need it," I said.

Later that afternoon, I watched joyfully as the iron lung was rolled out of my room. The next day, the oxygen tent

was removed. I had won a major victory; I could breathe by myself.

A nurse gave me more good news: I was moving out of isolation.

"Does that mean I'm not contagious anymore?" I asked.

"That's right. Your parents won't have to put on gowns, masks, and gloves before they visit you." Above her mask, her eyes smiled at me. "And neither will I," she added.

She opened a large bag and began dropping get-well cards into it. I had received dozens of cards and small gifts from family and friends. I had a faint memory of Mother and Dad holding up cards for me to look at through the oxygen tent and telling me who had sent them, but I had been too sick to pay attention.

The window ledge and the bedside table were crowded with cards, stuffed animals, books, and a flowering plant.

As I watched the nurse put a stuffed cat into her bag, I assumed she was moving my belongings to my new ward.

"This afternoon I'm going to have Mother read all my cards to me," I said. "I was so sick when they came that I don't remember who sent them."

"You can't take these cards to your new room," she said.

"Why not? They're mine."

"Anything you had in this room gets burned," she said. Humming cheerfully, she dropped my new books into the bag.

Chapter 4, *Small Steps: The Year I Got Polio* by Peg Kehret; published in 1996 by Albert Whitman & Company.

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To order, send a check for \$14.95 (please include the title of the book) to: Albert Whitman & Company, Customer Service, 6340 Oakton Street, Morton Grove, Illinois 60053-2723, or charge by phone: 800/255-7675 or 847/581-0033 in Illinois.

✿ Recognizing that nurses are important "screeners," coordinators, and advocates in healthcare, polio survivor Patti Strong has teamed with Maureen Habel, MA, RN, in writing articles for nursing publications. "The Late Effects of Poliomyelitis: Nursing Interventions for a Unique Patient Population" was published by *MEDSURG Nursing* (Vol. 5, No. 2) in April 1996.

Most recently "Providing excellent care for patients with post-polio syndrome, Part I," was published in *NURSEweek* (Vol. 10, No. 2), which is mailed to qualifying licensed registered nurses in designated counties in California and Texas. Part II has just been published in *NURSEweek* (Vol. 10, No. 3).

Back issues are available from NURSEweek Corporate Office, 1156-C Aster Avenue, Sunnyvale, California 94086-6801, USA for \$3.00 each.

John Haven Emerson

J.H. Emerson, inventor and businessman, died from cancer February 4 at the age of 90 in Cambridge, Massachusetts, his long-time home.

In 1931, Emerson developed a less costly, quieter, and more simplified model of an iron lung, which saved the lives of many polio survivors and ultimately became the most recognized image of the polio epidemics.

POST-POLIO BIBLIOGRAPHY

Bruno, R.L., Zimmerman, J.R., Creange, S., Lewis, T., Molzen, T. & Frick, N. (1996). Bromocriptine in the treatment of post-polio fatigue: A pilot study with implications for the pathophysiology of fatigue. *American Journal of Physical Medicine and Rehabilitation*, 75 (5), 340-347.

Richard L. Bruno, PhD, lead author of the article, explains that bromocriptine is an anti-Parkinson's medication. The five individuals (of the eight who qualified) who participated in the placebo-controlled trial were polio survivors who had paralytic polio and continued to report moderate to severe daily fatigue after complying with standard treatments such as conserving energy, pacing activities, and using assistive devices. These polio survivors represented 10% of the outpatient polio survivors without comorbidities seen at Kessler Institute for Rehabilitation over a period of time. In other words, 90% of the polio survivors improved with the standard treatment. Of those on the medication, three reported significantly less morning fatigue and less trouble staying awake during the day on the medication versus the placebo. All taking bromocriptine reported nausea.

The article warns "... the safety of bromocriptine remains a concern. Given the association of nausea and syncope (fainting or suspension of consciousness) in one subject, dopamimetics may be contraindicated in polio survivors with a history of syncope or even in those with bulbar polio that damaged brain stem cardiorespiratory centers."

Post-Polio Directory - 1997 is now available. Individuals who pre-paid will receive their copies soon. On behalf of individuals who are no longer listed, particularly former support group leaders and their families, International Polio Network requests that referrals not be made from old directories. For a copy of the *Post-Polio Directory - 1997*, send \$4 USA; \$5 Canada/Mexico and overseas surface; \$6 overseas air. The *Directory* is for information purposes only.

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Also publisher of
Rehabilitation Gazette and *I.V.U.N. News*

PROGRESS REPORT ON PBS DOCUMENTARY

In the June 1995 *Rehabilitation Gazette* (Vol. 35, No. 2), we published a request by the Center for History in the Media, George Washington University, which was collecting memories and documents of polio. Many of you responded to their plea.

Nina Seavey, the film's director, reports progress on *A Paralyzing Fear: The Story of Polio in America* continues in earnest. She has completed principle photography on the project and is making final preparations to edit massive amounts of interview and archival material.

Over the past four months, Seavey and her film crew have toured 6 locations around the country, filming over 40 interviews with polio survivors, doctors, nurses, research scientists, and other voices from the era of the polio epidemics. An interview trip to Alabama in March to record the story of Tuskegee University's involvement in the fight against polio will bring the production process to a close.

Ms. Seavey also obtained a stock of over 3000 films and 5000 photographs from the March of Dimes Birth Defects Foundation. The extensive research effort to view the entire archive has recently concluded and preliminary selections for editing have been made.

With help from the World Health Organization, the Centers for Disease Control, and Rotary International, Seavey visited India in January to witness the ongoing fight against the disease there and to document the efforts of the Target 2000 campaign for a polio-free world by the year 2000.

A Paralyzing Fear: The Story of Polio in America is slated to air on PBS in 1998.

calendar

1997

Polio Perspectives '97, MARCH 22-23, Bethesda Marriott Hotel, Bethesda, Maryland. Contact: Polio Society at 301/897-8180.

Southern Arizona Conference on Post-Polio Syndrome, APRIL 12, Holiday Inn Palo Verde Hotel & Conference Center, Tucson, Arizona. Contact: Polio Epic, P.O. Box 17556, Tucson, Arizona 85731 (520/750-8608).

Been There, Done That, Movin' On, SEPTEMBER 12-13, Atlanta, Georgia. Contact: Atlanta Post-Polio Association, P.O. Box 250566, Atlanta, Georgia 30325 (404/350-7631; 770/232-7178 FAX; laslinda@mindspring.com).

SEVENTH INTERNATIONAL
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MAY 29-31, 1997,
St. Louis Marriott
Pavilion Downtown.

Complete program and registration information was published in *Rehabilitation Gazette* (Vol. 37, No. 1), which was mailed to all subscribers. Please call G.I.N.I. at 314/534-0475 to receive additional copies.