

Polio Network News

Use of Medication in People with Post-Polio Syndrome

Susan Perlman, MD, University of California Los Angeles (UCLA)

Until we better understand the causes of post-polio syndrome, we will have no curative medication. At best, we can use medication to treat the symptoms and to improve the quality of life, and we can avoid using medication that could make the symptoms worse. Certain other diseases (elevated blood cholesterol levels, high blood pressure, heart disease, and cancers) require use of medications with side effects that can exacerbate symptoms of post-polio syndrome. These should be used, but with careful monitoring of the polio survivor's functioning.

Symptomatic Medication

The three primary symptoms that we can treat with medication are weakness of muscle, fatigue (individual muscle and generalized), and pain, i.e., post-polio pain, overuse pain, bio-mechanical pain, and bone pain (Gawne, AC, 1995).

Drugs to reverse muscular atrophy or to improve muscle strength by stimulating motor nerve endings to reconnect with muscle fibers (*nerve growth factors*) are all still experimental. They are currently being tested for use with other motor nerve diseases. Only insulin-like growth factor type 1 (IGF-1), also known as myotrophin or somatomedin-C, has been tested in people with post-polio syndrome (Miller, RG, 1997). (See chart on page 3.) It brought no change in strength or fatigability, but did improve recovery from fatigue after exercise. Human growth

hormone has been given to increase a person's natural level of IGF-1, but showed little or no improvement in strength (Gupta, KI, 1994).

Another approach has been to develop and test drugs that would protect the nerve-muscle connection from new damage in the first place (*neuro-protective agents*). Again, several have been studied in other diseases, but only selegiline has been tested in post-polio syndrome, bringing some improvement in symptoms but no clear stabilization of the disease (Bamford, CR, 1993). Although many people use over-the-counter antioxidant preparations of various types, these have never been formally tested to prove any ability to slow down the changes of post-polio syndrome.

Anabolic steroids, often used by body builders to improve muscle bulk and power, have been tried by polio survivors and other persons with neuromuscular diseases, but *The Medical Letter on Drugs and Therapeutics* reports the side effects (risk of prostate cancer in men, masculinization in women) greatly outweigh the potential benefits. *Metabolic stimulants* (L-carnitine*, L-acylcarnitine, co-enzyme Q), used to improve the ability of muscle to make energy and possibly reduce fatigue and improve strength, have also been tried by polio survivors, but have been associated with rare allergic reactions and insomnia (Lehmann, T, 1994; Nibbett, J, 1996).

Specific *anti-fatigue drugs* can act either in the brain itself (on pathways controlled by dopamine and noradrenaline) or by improving communication at the nerve-muscle connection. These are, respectively, central and peripheral agents. Centrally-acting anti-fatigue medications include amantadine, bromocriptine, selegiline, pemoline, ephedrine, and certain antidepressants (selective serotonin re-uptake inhibitors, which may also have nonadrenaline activity). All have been tested in other fatiguing neurologic illnesses, but only the first three have been studied in post-polio syndrome. Amantadine provided no reduction in fatigue (Stein, DP, 1995), but bromocriptine (Bruno, RL, 1996) and selegiline (Bamford, CR, 1993) did. Several studies have been done using pyridostigmine, a peripherally-acting drug, (Trojan, DA, 1993, 1995; Seizert, BP, 1994; Trojan, DA, 1997) that reflected variable effects on fatigue, possible mild improvement in strength in very weak muscles, and notable side effects (primarily gastrointestinal).

When contemplating the use of anti-fatigue drugs, we first treat any concomitant problems (other medical or neurological illnesses, sleep disorders, depression) that could be adding to fatigue.

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When rehabilitation techniques have not given adequate *pain relief* and medications must be used, we determine where the pain is coming from before choosing the most specific treatment agents. In our experience, for true post-polio muscle pain, centrally acting, non-narcotic drugs work best (serotonin-stimulating medications, e.g., tricyclic antidepressants, clonazepam, tramadol; central nerve relaxants, e.g., baclofen, tizanidine; nerve stabilizers, e.g., anticonvulsant drugs like carbamazepine or gabapentin).

Fortunately, we have no drug for overuse pain. If we did, using it would be like taking the batteries out of a smoke detector because it is noisy at night. This pain makes polio survivors aware that they are overdoing and need to cut back.

Biomechanical pain resistant to non-drug strategies may respond to short-term use of non-steroidal anti-inflammatory drugs (NSAIDs). Some survivors may experience the side effect of gastrointestinal problems.

Joint-related pain may require cautious long-term anti-inflammatory therapy. When a true analgesic is required, whether it is as simple as acetaminophen or as strong as a narcotic, it should be taken in moderate amounts and on a schedule, not just when the pain is so severe that a higher dose is necessary. If taken together, mild antihistamines or anti-anxiety medication may make painkillers

work better and at a lower dose, but do have their own side effects.

Acupuncture, electro-acupuncture, acupressure massage, and possibly magnetic therapy may work on painful muscle areas along the same pathways as narcotics, and all have been tried in post-polio syndrome. Pain caused by fibromyalgia may respond to low, bedtime doses of amitriptyline (Trojan, DA, 1994).

Cautions about Medications

Many drugs may have drowsiness as a side effect or may increase fatigue within the general population. (Always check the label or ask the pharmacist or physician.) These include central nervous system (brain) depressants, e.g., narcotics, sedatives, tranquilizers, sleeping pills, and alcohol; antihistamines; antidepressants; and anti-anxiety agents. Polio survivors who take these medications may experience an increase in polio-related weakness and fatigue.

Diuretics (water pills) and laxatives may deplete the body of essential minerals required by nerves and muscles for normal functioning. Many other drugs (antibiotics, chemotherapy agents, even megadoses of some vitamins, e.g., B₆) can contribute to nerve damage. Muscle relaxants and drugs similar to them in chemical structure (quinine, quinidine, procainamide), as well as other medications used for heart or blood pressure problems (beta-blockers, calcium chan-

Post-polio syndrome is a constellation of new symptoms (fatigue, weakness, pain, cold intolerance, muscle atrophy, or new problems with activities of daily living), occurring in survivors of definitively (by history, exam, or electrical studies) proven acute poliomyelitis, after a period of at least 15 years of stable recovery and performance, and in the absence of any other medical or neurological condition. It is felt to result from the weakening and loss of previously recovered lower motor neuron connections to muscle, possibly due to aging, greater fragility of the recovered nerves, or immune system dysregulation. Onset can be insidious, progression is usually slow, and treatment is most successful with rehabilitation strategies.

— SUSAN PERLMAN, MD

nel blockers), may add to polio-related weakness and fatigue.

Anecdotal evidence suggests that cholesterol-lowering medications of the "statin" family may also increase polio-related weakness and fatigue. Polio survivors, particularly those with a lesser muscle mass, have reported fewer and less dramatic side effects from some medications when taking a lower dose.

Polio survivors and their physicians should scrutinize all medications – current and newly added – used to treat various medical problems to be assured that related conditions, such as fibromyalgia, elevated cholesterol, high blood pressure, etc., are appropriately treated, but with minimal effect on polio-related symptoms. ■

*A placebo-controlled study, as yet unpublished, recently done in Germany showed no significant difference between placebo and L-carnitine.

Susan Perlman, MD is Associate Clinical Professor of Neurology and Director of the Post-polio Clinic at UCLA. Since 1988, the clinic has evaluated and treated 600 polio survivors, with an approach combining neurological assessment, neurorehabilitation techniques, medication intervention, and consultation with associates in orthopedics, medicine, sleep disorders, psychology, and alternative (complementary) medicine. The clinic coordinates with the dedicated support groups in southern California and offers educational outreach to the health care community.

Table. Pharmacology of Post-Polio Syndrome: Recent Trials

Drug	Category	Type of Trial	N	Results in PPS
Amantadine	Anti-viral	Randomized, placebo-controlled trial	25	No significant improvement in fatigue ¹
Prednisone (high-dose)	Steroid, anti-inflammatory	Randomized, placebo-controlled trial	17	No significant improvement in strength or fatigue ²
Human growth hormone	Hormone	Open trial	5	Little or no improvement in muscle strength ³
Bromocriptine	Dopamine receptor agonist	Placebo-controlled, cross-over trial	5	Improvement in fatigue symptoms in 3 patients ⁴
Selegiline	Neuro-protective agent	Case studies	2	Improvement in PPS symptoms ⁵
Pyridostigmine*	Anti-cholinesterase	Open trials	17, 27	Improvement in fatigue ^{6,7}
		Placebo-controlled, cross-over trial	27	Improvement in fatigue, strength ⁸
Insulin-like growth factor 1 (IGF-1)	Growth factor	Randomized placebo-controlled trial	22	Improvement in recovery after exercise, change in strength, fatiguability ⁹

¹Stein DP et al. A double-blind, placebo-controlled trial of amantadine for the treatment of fatigue in patients with the post-polio syndrome. *Ann NY Acad Sci* 1995;753:296-302.

²Dinsmore S et al. A double-blind, placebo-controlled trial of high-dose prednisone for the treatment of post-poliomyelitis syndrome. *Ann NY Acad Sci* 1995;753:303-313.

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⁴Bruno RL et al. Bromocriptine in the treatment of post-polio fatigue. *Am J Phy Med Rehabil* 1996;75:340-347.

⁵Bamford CR et al. Postpolio syndrome response to deprenyl (selegiline). *Int J Neurosci* 1993;71:183-188.

⁶Trojan DA et al. Anticholinesterase-responsive neuromuscular junction transmission defects in post-poliomyelitis fatigue. *J Neurol Sci* 1993;114:170-177.

⁷Trojan DA, Cashman NR. An open trial of pyridostigmine in post-poliomyelitis syndrome. *Can J Neurol Sci* 1995;22:223-227.

⁸Seizert BP et al. Pyridostigmine effect on strength, endurance, and fatigue in post-polio patients (Abstract). *Arch Phys Med Rehabil* 1994;75:1049.

⁹Miller RG et al. The effect of recombinant insulin-like growth factor 1 upon exercise-induced fatigue and recovery in patients with post polio syndrome (Abstract). *Neurology* 1997 (in press).

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*An article detailing the results of the North American Post-Poliomyelitis Pyridostigmine Study (NAPPS) has been submitted for publication.

Post-Polio Bibliography

◆ Wilson, D. (1998). A crippling fear: experiencing polio in the era of FDR. *Bulletin of the History of Medicine*, 72, 464-495.

Polio survivor and professor at Muhlenberg College, Allentown, PA (Pennsylvania), explores published polio narratives, transcriptions of oral history interviews, and letters written to President Roosevelt during the polio epidemics between 1930 and 1945.

This exploration beyond the public polio image created in the popular press and medical writings reveals a more complex picture of the polio experience than encompassed in previous accounts.

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Gary with his wife, Belinda, and sons, Christopher (center) and Matthew.

The Air That I Breathe

Gary Presley, Aurora, Missouri

That which God manages with a diaphragm, a few muscles, and involuntary muscle response can be mimicked satisfactorily by a Bantam positive-pressure machine.

Noisy? Yes, and when I used one, I always had the problem of balancing the pressure to achieve sufficient ventilation with the nasal mask's tendency to plow a furrow in my nose.

Nevertheless, only an ingrate would begrudge the source of the air rippling down the hose – air meaning renewed health and vigor to some of us post-polio people. I gladly strapped on the little rascal each night. The noise and the intermittent sore nose assured me, "I'm still here."

Thus, when the representative from LIFECARE (now Respironics) called about four years ago and suggested I change from the Bantam to the PLV-100, I was reluctant. Why leave behind the lively little machine that brought me back from respiratory collapse? I was addicted to the sound of the Bantam wheezing away into the night: I could not sleep without it.

I never asked, "Why did you pick me to volunteer?" I just assumed that one glance around our house – stacked with computers, ham radios, scanners – confirmed that I was a boy who never outgrew his toys.

Moreover, I have always realized that technology means progress. The Bantam design dates back decades: support for its maintenance – parts and expertise – dwindles. I could see that I had to

take the plunge sooner or later and switch to a readily serviceable machine.

After my doctor cleared the changeover, the representative, on his next trip to the Ozarks, hauled a PLV-100 in the door. One look confirmed we had moved into a fancier neighborhood in Gadgettown.

My Bantam had one pressure gauge, a toggle switch or two, a fuse, and a rotary dial – simple and effective. The PLV-100, on the other hand, sports four LCD readouts, seven rotary switches, and a pressure gauge.

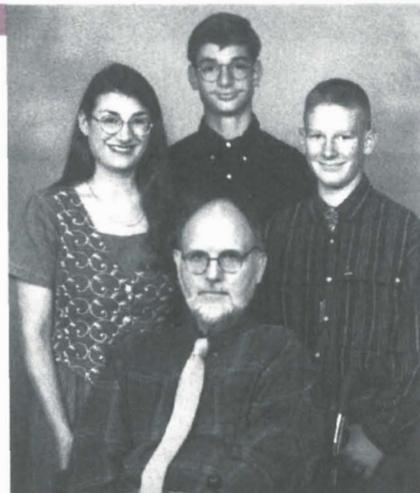
No denying that this technological overkill caused me to catch my breath, if you will pardon the reference. All this to blow a volume of 1200 to 1400 cubic centimeters of air up my nose sixteen times a minute while I sleep?

The PLV-100 measures the air in volume rather than by pressure. That one factor – airflow being regulated by volume rather than by pressure – seems to be the fundamental difference. Thinking about the switch in that fashion helped me realize that the complex assortment of gauges and dials only mask the simplicity of the changeover.

I let the respiratory technician balance the gauges and explain their function. My job was to learn how much volume would make me comfortable and the rate at which I wanted it.

The first thing you'll notice is the PLV-100 is quieter than the Bantam. Personally, I took comfort in the mechanical wheeze and clunk of the Bantam, but others, like the people in your house, will appreciate the PLV-100's quieter mechanism. My wife does, I know.

You will also appreciate the decreased wear and tear on your nose. I ran the Bantam at approx-



imately 25 pounds of pressure to sleep comfortably. The PLV-100 delivers 1400 cc of air at about 15 pounds of pressure. That missing 10 pounds of air pressure allows my nose to wake up nearly as refreshed as the rest of me.

The first night following my switch-over went smoothly, although I would be deceitful to say that changing from a Bantam to a PLV-100 does not require a period of adjustment. Mine was short, mainly requiring me to understand that the lesser amount of pressure did not translate into a lesser amount of air.

I had noticed a feeling of claustrophobia developing over the last several years, a trapped feeling amplified if I do not receive proper ventilation while lying in bed.

No surprise then that the first minute or two of the changeover from a pressure ventilator to a volume ventilator left me feeling as if I was not getting an adequate amount of air down the hose, but the feeling lasted only a few minutes.

After a night or two, even that initial feeling passed. I was "breathing" while asleep. I felt well rested and comfortable when I woke up in the morning.

My transition became a matter of relaxing into the rhythm of the PLV-100. I am a relatively light sleeper, and, even when I am resting well, I wake up two or three times a night. Despite my anxiety

about the reduced pressure, I found I was resting properly and felt "ventilated" (for want of a better term) rather than out of breath when I woke up in the middle of the night.

By the third night, the PLV-100 had become a member of the household. In fact, in the two instances when I have had trouble with the PLV-100 and been forced to rely on my spare Bantam, I found reacclimatizing myself to the Bantam more difficult than switching from the Bantam to the PLV-100.

The PLV-100 is a practical improvement over the Bantam as well. It is smaller and built in a durable square case, complete with rack handles. It sports a front-face plug-in adapter for 12-volt emergency use. Better yet, it has an internal NiCad battery system that provides about one hour of operating time during power outages.

Do I miss the Bantam? No. Would I encourage Bantam users to switch to the PLV-100? Yes. Those two questions I can answer easily. The final question is harder: will it be difficult for a long-term Bantam user to make the switch?

I cannot answer for you. In my experience, I found the switch remarkably easy. Why? A positive attitude about positive pressure, I expect. The late effects of poliomyelitis are real, but I refused to listen, and found myself in the ICU suffering from the effects of improper ventilation. Nighttime positive pressure rescued me, and I began to understand that proper nighttime ventilation is my key to good health.

Thus, I learned, and, when the PLV-100 was offered and its benefits explained, I believed. ■

The Switchover

Richard Wieler, Columbia, Missouri

My reason for switching from a pressure ventilator to a volume ventilator was simple: my doctor suggested it. In this respect, I have been very fortunate to have a physician with experience in dealing with chronic hypoventilation.

I had left assisted breathing far behind in 1956 after a year in a polio ward, graduating from the iron lung, the chest cuirass, and the rocking bed. Twenty-five years later, the return was troubling. However, I had to return because of the inadequate exchange of gases during the night and the need to rest my weak diaphragm. Moreover, my sleep was very disturbed because of the buildup of carbon dioxide.

At first, I was refitted with a chest cuirass, which I used for several years, but it became apparent that the "shell" was no longer effective because of permanent scoliosis. A local physician suggested returning to the iron lung. No way! Then, I was introduced to pressure ventilation. Once I got used to the face mask, non-invasive ventilation with a pressure ventilator seemed to work well: I was finally getting a good night's rest and feeling refreshed in the morning.

Finally, after five years, I switched from pressure to volume ventilation because my doctor was still not satisfied with my test results. My arterial blood gases disclosed that my carbon dioxide readings were still too high. Since a pressure ventilator pushes air only to a preset level, the actual amount getting into the lungs can be lessened by any obstruction, including the tightening of the chest cavity during long periods of being

prone. In my case, too, allergies presented a steady impediment. Colds were also a big problem because of the blockage of air passageways with sputum. On the other hand, a volume ventilator is set for a certain volume of air, regardless of the pressure. I spent one night in the hospital so that my doctor could set the adjustments on my PLV-100 volume ventilator using my blood gases to check the results. He set it to push out 1.05 liters of air fourteen times a minute. I spend nine hours a night on this setting, and my blood gases are checked periodically to be sure I am adequately ventilated, usually once a year.

The PLV-100 has the added feature of giving me a larger breath upon demand, activated by my consciously inhaling much like sighing. Although the unit is bigger than my old pressure ventilator and has more controls, it is easily mastered and very dependable. Breathing during the night is much smoother, and I have fewer colds because the volume ventilator insures more air and assists in coughing. Of course, the hunt to find a mask that fits perfectly continues, and will forever, I fear. However, the switch to the PLV-100 ventilator has been positive for me. ■

International Ventilator Users Network (IVUN), also coordinated by Gazette International Networking Institute (GINI), publishes the quarterly *IVUN News*, a newsletter for ventilator users and health professionals interested in mechanical ventilation and home care. Subscription fees are \$17 USA, \$22 Canada, Mexico & overseas surface, and \$27 overseas air. The *IVUN Resource Directory* is available for \$5 USA, \$6 Canada, Mexico & overseas surface, and \$7 overseas air.

Adios, Weight!

LaVonne Schoneman,
Seattle, Washington

Is it possible to feel stronger and healthier, have a better mental outlook, look better, suffer less pain ... and even lose weight when you have the late effects of polio?

My 40th high school reunion was coming up, and I wondered if I would be up to going. Some classmates refuse to attend because they imagine they have grown too old, too fat, too bald. Would I feel like it physically?

I was diagnosed in 1996 with type 2 diabetes, formerly called adult-onset or insulin-independent diabetes, and I had to face the fact that my own diet was killing me.

First I had the flu – a very bad case, then a bladder infection, finally a diagnosis of type 2 diabetes. The symptoms crept up on me, and I mostly blamed post-polio. (Warning: Get a simple glucose test when having a routine medical examination.)

About this time, my sister-in-law lost her sight and one leg to diabetes. She refused to modify her diet. “Face it,” I told myself, “it could be you losing a limb.” I did not want to lose my sight or end up with gangrene, losing even one toe. My plan was to stay alive, get well, remain healthy – but how?

Time to face facts! Was my inability to accept my post-polio what caused me to fill the void with chocolate and fifty unneeded pounds? Would my diabetes do me in even though I had won out over polio and its late effects?

Since my 1950s case of polio I had faced challenges. Over the years I had gone from an active lifestyle of chasing three small

children through the 1970s to climbing ruins in Mexico, mushroom hunting in the woods, and ballroom dancing in the 1980s. In the 1990s, ill health forced me into early retirement and a sedentary lifestyle, using a wheelchair.

I learned to cope with my new physical problems in several ways. The support of a caring spouse was my mainstay. Since sitting was fast becoming my primary new skill, I began writing again.

For five years I wrote “LaVonne’s Coping Column” for a post-polio newsletter serving the Pacific northwest. The readers’ gratifying response led to four *How to Cope* books filled with coping tips and articles. Coping with new physical disability, weakness, overwhelming fatigue, and new pain is no joke. Writing poetry and seeing it published helped me regain my self-esteem. But my eating habits were out of control.

You would think I would be equipped to handle any challenge. Right? Wrong! Choosing to love myself enough to regain my health was not easy.

All my life I had been told that I was borderline diabetic and to be careful. This well-meaning advice meant little to me without the education or tools to take control of my own body. I had educated myself and health care providers about post-polio, had quit smoking and drinking ... so, how would I now control my diet?

My husband and I collaborated on rewriting our family recipes, creating a new cookbook while practicing a new diet. We read every book written about diabetes (our library had dozens), acquired a blood sugar/glucose meter, new (sit-upon) scales, and a wrist-style blood pressure monitor to use at home. We learned to scrutinize and understand food labels.

Ruthlessly, we threw out all the food products containing sugar. We also got rid of products that contained too much fat or sodium. This job was not much different than what we had done when I had become allergic to sulfites, nitrites, and preservatives.

“Think of this as our daily exercise,” my husband encouraged. Without his help it would have been harder, maybe impossible.

We said “adios” to all the food we loaded into a carton for the local food bank. And to a list of favorites. Adios to ... BLTs with real bacon ... sausage and gravy on biscuits and fried eggs and fried everything ... lattés with hot buttered cinnamon rolls ... takeout, home delivery, and tv dinners.

“Look, I copied the information out of all the books we have read and created a pocket-sized, instantly available booklet to double-check my food exchanges,” I declared a few weeks after we had begun my new diet. My husband read the daily list aloud, “1 milk, 2-3 fruits, 5-6 veggies, 6 fats, 9 starches, 2 ounces of meat.” Then he gave me a big hug.

The ideal amount of calories for someone my height of 5’2”, is 1500-1800 per day. My husband eats more, commensurate with his size. At dinner we always serve two vegetables and a green salad. Six to eight small snacks at regular intervals throughout the day also help keep me on target.

Weight loss was apparent immediately. Within six months, I had lost fifty pounds!

My husband, who unasked, went along with this new diet program, saw his belt size shrink three notches. As my weight melted away, I was left feeling stronger and more in control of my body. I bought some pretty new clothes and smaller lingerie. My husband’s

loving, non-judgmental support helped make it possible to shed those unneeded pounds.

A side benefit was an immense easing of my post-polio pain. As my health improved, so did my outlook.

At Halloween we passed out candy to the neighborhood children. One container had sugar-free candy and the other did not. Often parents commented on the thoughtful gesture of offering sugarfree snacks, and both disappeared at an equal rate. We cannot convert the world's eating habits, but we feel better about ourselves. Rather than face leftover candy the next day, we gave it to the first grandkid who visited.

Cooperation from my family is important. I know my husband occasionally treats himself when out of my sight, but that is okay with me. He is not the diabetic one, nor the post-polio one. I will not deprive him of making his own food choices.

Recently, my daughter commented, "Look, Mom, you have wrists again!" Grinning at my reflection in the window, minus the extra chins, I waved adios to the departing grandchildren ... and the Halloween candy.

Recently, my doctor pronounced my diabetes under excellent control. Can the cure for one disease really cure another? No, but the treatment for one can greatly alleviate the symptoms for the other.

I did celebrate my 40th high school reunion this summer – minus fifty unneeded pounds and with all my toes intact! My former classmates gathered around me and made me feel as popular and welcome as when I was voted the "biggest flirt of the class of 1958." ■

My Typical Daily Food Plan

6-8 small meals or snacks, 2-3 hours apart, 1500-1800 calories each day (using my personal diabetic food exchange list)

WHEN I GET UP IN THE MORNING, I START MY DAY WITH:

- 1/3 cup plain yogurt with 1 TB berries
- 6 oz orange juice (lite, cut with 50% more water)
- 2" slice fresh melon
- 2 oz sauerkraut juice, which promotes regularity (135 calories).

MY LARGEST MEAL OF THE DAY IS LUNCH WHICH INCLUDES:

- 1 large mixed green salad with lite dressing
- 2 servings of spinach, zucchini, carrots, etc.
- 2 oz meat (size of a deck of cards; use postage scale to weigh) – eye of round, lean pork steak, or hamburger patty **or** substitute 1 egg **or** 2 oz cheese or 1/2 cup cottage cheese (never exceeding in the same day)
- 1 medium baked or boiled potato, **or** one-half cup rice or pasta, with low-fat margarine, lite sour cream, soya bacon bits (approximately 300 calories)

A TYPICAL DAY'S SNACKS COULD INCLUDE:

- ◆ 6 oz V8 or tomato juice, 2 Keebler crackers* (70 calories)
- ◆ 1/2 serving of fruit – apple, pear, orange, grapes – or 1/2 cup applesauce (35-50 calories)
- ◆ One diet soda and one 6-pack Keebler crackers* and one packet Metamucil (I hate spending 100 calories this way, but between sauerkraut juice and Metamucil daily, I have stopped having constipation due to a sedentary lifestyle.) (190 calories, plus 100 for Metamucil)
- ◆ 1/2 cup diabetic ice-cream with 1/2 banana (100-150 calories)
- ◆ Two tiny sandwiches of cucumbers, alfalfa sprouts, lettuce, tomato, and a bit of preservative-free turkey lunchmeat (very hard to find without preservatives/nitrites) on 4 slices party rye bread and 2 (yes, 2!) potato chips and one dill pickle or 2 to 3 olives (This is my BIG snack – 100-150 calories)
- ◆ 6 oz watered-down lite/sugarfree fruit juice and 6 Keebler crackers with lite cream cheese. (200-245 calories)

Additionally: veggie sticks; sugarfree jello, pudding, candy, gum, soda; tea; coffee (25 calories)

Total calories = 1335 (leave wiggle room of 165-465 calories)

You can train your eyes and tummy to be satisfied with smaller servings, I promise! Fill up on vegetables and salad when you are extra hungry. I use Nutrasweet and Sugar Twin; applesauce is a natural sweetener. I limit or avoid cheese, eggs, dry beans, corn, and bread. Bread must be rationed; I routinely discard the inner third of a hamburger bun.

*I use Keebler Cheese & Peanut Butter Sandwich crackers in my calculations, which are packaged in convenient 6-packs, lack preservatives, and seem to be lower in sodium and fat than many other brands.

The secret is knowing you will be allowed more food in a few hours so you never feel deprived.

I follow a vitamin regimen and avoid all preservatives.

My diet is overseen by my personal physician.

Polio in Thailand

Sunan Willcox, Thailand

Polio has had a devastating impact in Thailand, not only because of susceptibility to the virus, but also because of public attitudes toward disability. The accepted and traditional Thai perception of disease has been that those who suffer are experiencing a direct payback for misdeeds experienced during previous incarnations. Further fallout from this perception has been that disabled persons are perceived as carriers of contagious misfortune, not only for themselves, but also for those around them. As if this were not a heavy enough burden, physical disability is also perceived by the public as a form of mental inferiority. When the average Thai adult sees a disabled person, there is an automatic assumption that physical and mental disability are one and the same.

As a society on the whole, Thai people are usually quite compassionate, but when compassion is applied to disability, it is traditionally expressed as pity, rather than understanding. Even the Thai medical profession (including those trained in the western universities) has often been negatively affected by these public misconceptions. Our foundation believes that polio in Thailand has not been adequately or carefully studied by health care professionals. The consequences have been that polio has often been misdiagnosed and confused with other neuromuscular diseases. An incorrect diagnosis has often resulted in incorrect treatment (especially outside of Bangkok). It is quite common to encounter people

with disabilities unrelated to polio who believe, because of professional medical advice, that whatever is wrong with them is called "polio." It is also not uncommon in rural areas for health professionals to have recommended amputation as a "cure-all," not only for polio survivors, but quite often for other neuromuscular diseases as well.

The most commonly recognized indication of polio in Thailand is the thousands of citizens who live with permanently bent, abnormal legs. Today, teenagers enter adulthood with this form of medical and social neglect. The situation of Khun Priyanute, a 20-year-old Thai female who recently attempted to attend a vocational training center in north Thailand, is an extreme example of what can and does still happen. Both of her legs had atrophied to the point where the only way she could navigate was to literally "duck walk" her way through life, knees spread apart. Khun's humiliation at having to expose herself to others, even among disabled persons, was so great that she eventually withdrew from school in order to remain at home. Her family remains without financial access to provide a surgical solution.

The future, however, does hold promise. Through UNESCO, WHO, Rotary International, and the Thai government, oral polio vaccine is now available in all parts of Thailand. Public attitudes are also slowly changing. Non-governmental organizations are bringing about change, and laws have recently been passed (though not yet enforced) to provide health care and accessibility for persons with disabilities.

As board president of the Foundation to Encourage the Potential of Disabled Persons (and as a polio survivor since the

Sunan, born in Thailand, is a graduate of Piyap University (at a time when she was the only disabled student on campus) and is a self-employed accounting consultant owning her own business. Sunan's husband, Don, is a social activist who earlier worked with indigenous people in Guatemala, then founded a disabled and orphan sponsorship program in Nepal called Hands in Outreach (now in its fifteenth year), and more recently set up the Foundation to Encourage the Potential of Disabled Persons to serve northern Thailand.

age of 5 months, currently using both forearm crutches and a long leg brace), I can say, without reservation, that it has been and continues to be an uphill struggle for polio survivors in Thailand. It is still extremely rare to find informed medical help or to encounter any form of physical access in private or public architecture, or in transportation. The result is that most polio survivors remain homebound, not by choice, but by necessity. Polio survivors often miss out on the vitality of the life around them because they are either so weary, or soul weary of being stared at and looked down upon, or because even such a simple event as buying an ordinary postage stamp in a public post office becomes a confrontation with flights of steps.

At the end of 1998, Bangkok hosted the Asian Disabled Games. We are hopeful that this major event in our country will encourage public awareness about physical disability in Thailand. ■

Foundation to Encourage the Potential of Disabled Persons

195/197 Ban Tanawan, Moo 8
Tambon Sanpheeseu, Amphur Muang
Chiang Mai 50300, Thailand
(66-53-240935, phone & fax)
assist@loxinfo.co.th
www.chiangmainews.com/
disabled/disabled.html

Readers Write

"I am looking for a solution to protect my specially-made (and expensive) shoes while I work on cars. I have been using plastic baggies over my shoes, but there must be a better way! Regular Totes-type rain boots for overshoes would be appropriate, but do not work because one of my shoes' soles is too high."

Tracy, California

"I went to the dentist and she prescribed Clindamycin, an antibiotic. I did not pay any attention to the blurb from the pharmacist, but thank goodness my husband read it. 'If you get hives, itching, or have trouble breathing, call your doctor and stop immediately.'

"I called Augusta Alba, MD, who told me it contained a neuromuscular blocking agent and advised against my taking it.

"Be careful and read your prescription labels!"

Florence, New York
(LUNDEFM@aol.com)

Polio survivors living in the Minneapolis, Minnesota area and interested in participating in a post-polio support group should call Murray at Independence Crossroads (612/854-8004).

"I have two complete iron lungs: J.H. Emerson, Serial #C/X115 (bellow on the end); and Iron Lung Company of America, Serial #2056 (repair by Scully Watson of Sacramento)."

Wes Bonifay, 11551
Nacogdoches Road, P.O. Box
33240, San Antonio, TX (Texas)
78265 (210/655-3010)

"The Absorbalite crutch tips described in the summer 1998 issue of *Polio Network News* may

not be appropriate for those individuals who can walk straight without too much wobbling from side to side (especially women of slight build) because the tips add unwanted weight and bulk to crutches. If, however, you are a large or heavy person, or tend to wobble a lot in your forward progress – the crutch tips can add stability and the additional weight may not make any difference."

Sunan, Thailand

Post-Polio Network Inc. of New South Wales, Australia, surveyed its members and has released a report entitled "Polio, A Challenge for Life: The Impact of the Late Effects," which contains an analysis of the results. The data highlight the difficulties experienced by polio survivors in relation to all aspects of life including mobility, daily life (personal care and household tasks), employment, and recreation. The report is available for \$22 (US dollars). For more information, contact:

Merle Thompson, Vice-President, Post-Polio Network (NSW) Inc., P.O. Box 888, Kensington, New South Wales, Australia 1465 (02-9663-2402, polio@fastlink.com.au, www.post-polionetwork.org.au)

Readers Respond

Readers suggested the following as sources for custom corsets:

Robert Wahlen, Scheck & Siress, 1411 Madison Street, Oak Park, IL (Illinois) 60302 (708/383-2257, 708/383-0739 fax)

ACTRA Rehabilitation Associates, 4500 Park Glen Road, Suite 390, Saint Louis Park, MN (Minnesota) 55416 (612/922-1055)

G.A. Guilford & Son, 13515 Brookpark Road, Cleveland, OH (Ohio) 44142 (216/362-1350 – ask for Skip Guilford)

MORE CRUTCHES, CANES, ETC. ...

The Mobility Aid Company

Mountain Properties, Ltd.
10821 Farms Road
Mission, BC (British Columbia)
Canada V2V 4J1

131 Harrison Street, #103
Box 159, Sumas, WA (Washington)
98295-0159

800/919-9699 or 604/826-9699,
604/826-9507 fax

Purveyors of daily use canes and fine walking sticks.

Kool Krutch, Inc.

4713 Dreyfous Avenue,
Metairie, LA (Louisiana) 70006
504/828-7739, 504/779-7066 fax
jsigsworth@aol.com/jsigsworth/
main.htm
http://members.aol.com/
jsigsworth/main.htm
www.webdynamx.com/universal/
kool-krutch-inc.html

Attractive and functional cushions and "hands free" carrying bags for standard and forearm crutches.

The Absorber Crutch Enhancer

can be fitted into existing metal forearm and underarm crutches or obtained connected to forearm crutches. They reduce shock and are available in black, silver, and blue. Model A700-63 fits 7/8" (2.2 cm) crutches and A700-632 fits ¾" (1.9 cm) crutches. Made by the Rehabilitation Division of Smith & Nephew, Inc. Contact your local adaptive equipment distributor.

Standers

1638 North 200 West, #C, Logan, UT (Utah) 84341 (435/755-0453, 435/787-2301 fax, sales@stander.com, www.stander.com)

Standers offer a variety of low-tech devices to assist people in getting to their feet (e.g., CouchCane™, CarCaddie™, and BedCaddie™).

Reactions to PBS Special

International Polio Network invited readers to voice their personal reactions to the PBS television special, "A Paralyzing Fear: The Story of Polio in America," written and produced by Nina Seavey.

Kathleen A. Navarre, PhD, Essexville, Michigan

My reaction to the film, "A Paralyzing Fear," ran the gamut from objective film critic to the very personal reliving of a long repressed event that seemed to happen to someone else, or in another lifetime, but also clearly happened to me. The event, polio in 1952, is at once an intimately personal experience, and at the same time a unifying event that binds all polio survivors who shared that experience. We are all unique individuals as polio survivors, yet one moment in time unites us: the moment the poliovirus changed our bodies and, therefore, our lives.

Regarding my personal reaction, there were some "flashbulb memories"; the kind of memory that is like a picture, as if the instant remembered was not in the past but a present experience. There were hot packs, too hot for the nurses to touch, so they handled them with gloves and tongs; the confining heat when first wrapped; then the feel of prickly, damp wool as it cooled off. There was the haunting rhythm of the iron lung and my hair being pulled by the rubber neck band as I was moved in and out several times a day.

For me, at the age of six, my hair being pulled was the biggest "trauma" of the day. For me, in 1998, the viewing of the film was painful in parts, helpful in parts.

As each individual shared his/her story, I felt less alone in my struggles.

The one personal and extremely profound insight I had was of polio's effect on my family and community. I showed a preview of the film to the polio survivors' support group that I chair. My eight-year-old, red-haired niece was with me for the meeting. At one point I looked over at her as she intently watched the film and was struck by the realization that my parents had to see their little red-haired girl being put in an iron lung and then leave the hospital to go home and raise four other children who were as confused and bewildered as I. Looking at my niece, I wondered how I could possibly handle her being paralyzed, and further wondered how I could cope with the sad faces that awaited at home. Life was changed for my family, and I now deeply respect their ability to handle this overwhelming illness with love and caring.

Polio as an epidemic had some unique features. It was not an individualized event; it was a public event that brought fear, compassion, and prejudice all at once. In my city of some 50,000, the daily paper posted who was hospitalized with polio that week. As the film showed, siblings suffered by being banished from some groups, not out of hatred but out of fear. As a child it does not matter why one is ostracized, one just feels the hurt. The support group concept that would have helped siblings and survivors cope with the emotional confusion was not generally available.

Now for the more objective critic's corner. People who viewed the film who had little prior knowledge of polio history (i.e., Warm Springs, Roosevelt's "Magnificent Deception," the Mother's March

of Dimes, and the vaccine controversy between Drs. Salk and Sabin), found the film interesting and enlightening. The overly dramatic "pitch" that Hollywood took certainly added to the "poor crippled poster child" image most of us have been fighting all our lives. The approach, along with its stereotypes, from the '50s lives on. I would have liked the film to comment on this, but it was an historical documentary, and in that narrow definition, did its job well.

I most take issue with the ending of the film. It ends as if the story of polio is only an historical one. As all polio survivors and their families and friends know, the polio vaccine ended only one chapter of the history of polio. Another chapter of post-polio syndrome has opened. The end of this new chapter has yet to be written. Without public knowledge and support, the final chapter is in jeopardy of a less than optimal ending. It is my hope that the film, "A Paralyzing Fear," is a catalyst in bringing new interest, knowledge, research, and support for the final chapter.

Martha Ericson Dale, PhD, Sun City, Arizona

"Absolutely outstanding!" is my assessment of the documentary. The film, underwritten by the National Endowment for the Humanities, makes use of the many motion pictures archived by the March of Dimes. Olympia Dukakis narrates the script in a matter-of-fact tone, without histrionics or pathos.

Vivid motion picture sequences show the devastating effects of polio on infants and young children. Their wasted muscles and immovable limbs with heavy metal braces and crutches provide a touching sight.

Polio was not a disease of the slums, but instead of clean, middle-class areas where children had not developed an immunity to the dreaded virus. And, furthermore, it was an illness that inspired concern and pity. The President of the United States, Franklin D. Roosevelt had, after all, become ill with polio.

Basil O'Connor, appointed by President Roosevelt to head the March of Dimes, knew there was no cure for polio – his intent was to prevent the disease from occurring at all. Although Dr. Albert Sabin and Dr. Jonas Salk differed in their approach to eliminating polio, eventually a vaccine was developed and field trials began. In April 1955, the Salk vaccine was announced with great fanfare, "It works!" And so began the program of vaccinations administered to infants and children. Today, the main thrust is to eliminate polio from Third World countries. It can be and must be done.

I would like to add a personal note. In 1952, I was at home with my 27-month-old twin sons and six-months pregnant. I was not concerned about their contracting polio. They were not involved with other children, but played in their own backyard. What I did not know was that pregnant women were unusually susceptible to the poliovirus. I contracted polio and all four limbs were affected. Before polio was diagnosed, I was admitted to the maternity section of Bon Secours Hospital in Grosse Pointe, Michigan. Once the diagnosis was made, the hospital administrators could not get me out of there fast enough, and I was sent to Herman Kieffer Hospital in Detroit.

Many adults were stricken that year, and, as shown in the documentary, we were treated with hot packs and exercise.

After the acute phase, I was off to a general hospital where it took three attendants and parallel bars to get me onto my feet. I was torn between tears and laughter at the mirrored sight of my pinhead hospital haircut, my bulbous pregnant middle, and my matchstick legs.

I joined a group of adult polio patients at MacGregor Rehabilitation Foundation which was like living in a private club with nursing care and, of course, those disgusting exercises. My most distasteful experience was practicing sitting down and getting up from a straight-backed chair. Descending a single stairstep while on crutches was terrifying.

Our third son, born in 1953, was taken by our pediatrician's wife for the first month of his life. Later, I was sent home from the MacGregor Foundation to my little twin boys and a month-old infant. I made sandbags in one, two, and five pound weights, using my baby scale to weigh the sand. I learned that no one really cared if I did my exercises or not, and there was no way to pay anyone to do them for me. So I had to do them myself. It was not a fun time. Through all this, my physician husband and his best friend, also a physician, formed a "shape-up, no nonsense" team, and the orthopedist who came to our house pointed to my wheelchair and said, "That's got to go!" I was so provoked that I called at once to have the rented wheelchair removed, thinking, "They'll be sorry when they see how tired I get!" It was the best thing that could have happened.

Eventually I regained the use of most muscles and gave up my crutches, although my left quads never recovered and were the cause of several falls for years afterward. My worst enemy was icy sidewalks. I learned that ener-

gy is like money – you can spend it any way you like, but when it's gone, it's gone. This is a lesson I'm still learning! The next few years saw my return to professional life as a university professor/clinical psychologist.

The film is an excellent summation of events involving the disease polio, including the great work of the March of Dimes and the Mothers' March on Polio that underpinned the funding of the research that made the vaccine possible.

The only thing lacking in the film is a tribute to the courage and determination of those boys and girls, men and women who managed to make a life and career for themselves. And beyond that, it lacked advice on how to find a handicapped parking place! ■

Other comments ...

"The film caused me to remember how guilty I felt when I was finally home from the hospital. My parents and neighbors were so welcoming and thrilled. I, on the other hand, was lonely and wanted to be back with my friends in the hospital."

Jack, Saint Louis, Missouri

"For years I had remembered the sparseness of the hospital and thought I had not received the best treatment. After viewing the film, I realized that all hospitals looked that way then."

Dorothy, Saint Peters, Missouri

"We contacted John Gibson, head of Toledo's Channel 30. After learning about the late effects of polio, he wanted to help and came up with the idea of having a member of our post-polio support group introduce the film."

Margaret Savage, Toledo, Ohio

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Post-Polio Directory 1999

will be available March 1st. Entries from 1998 are being confirmed. Listings include clinics and health professionals knowledgeable about the late effects of polio, and support groups. The cost is \$5 USA, \$6 Canada, Mexico, and overseas surface; and \$7 overseas air.

Calendar

International Polio Network (IPN) invites all post-polio related groups to submit details of upcoming meetings. Send the name of the event, dates, location, and contact information to Sheryl R. Prater at GINI, 4207 Lindell Boulevard, #110, Saint Louis, MO (Missouri) 63108-2915, 314/534-5070 fax, or gini_intl@msn.com.

1999

Polio in the 21st Century, MARCH 12-13, Green Isle Hotel, Dublin, Ireland. Featured speakers include: Jacquelin Perry, MD, Downey, California; Orla Hardiman, MD, Dublin, Ireland; and Frank Lønnberg, MD, Denmark. Contact: Post Polio Support Group, Carmichael Centre, North Brunswick Street, Dublin 8, Ireland (353-873-0338, 353-01-283-1409 fax, or ppsg@tinet.ie).

7th International Conference on Home Ventilation, Noninvasive Ventilation: Across the Spectrum from Critical Care to Home Care, MARCH 14-17, Caribe Royale Resort Suites, Orlando, Florida. Featured speakers include: Barry Make, MD, FCCP, Denver, Colorado; Dominique Robert, MD, Lyon, France; Augusta Alba, MD, New York, New York; John Bach, MD, FCCP, Newark, New Jersey; Alan Fiala, PhD, Falls Church, Virginia; Allen I. Goldberg, MD, FCCP, Maywood, Illinois; Edward Oppenheimer, MD, FCCP, Los Angeles, California; Patrick Leger, MD, FCCP, and Susan Sorter Leger, RRT, Boulogne, France.

New Hampshire Post-Polio Conference, MAY 1, Wentworth-Douglass Hospital, Dover, New Hampshire. Featured speakers include: William Clinton Maxwell, MD, Plano, Texas. Contact Deborah Thibodeau, 25 Buffumsville Road, Somersworth, NH (New Hampshire) 03878 (603-692-5877).

Annual Ohio Post-Polio Network Conference, AUGUST 21, Samaritan North Health Center, 9000 North Main Street, Dayton, Ohio. Featured speakers include: Jane Wootton, MD, Richmond, Virginia. Contact Shirlee Sussman, 6560 Semley Court, Dayton, OH (Ohio) 45415 (937-890-0205 or scrappiew@aol.com).

Post-Polio Conference, SEPTEMBER 17, Embassy Suites Hotel, 555 South 10th Street, Omaha, Nebraska. Featured speakers include: Burk Jubelt, MD, Syracuse, New York. Contact Marian Barnett, Nebraska Polio Survivors Association, P.O. Box 45139, Omaha, NE (Nebraska) 68145-0139 (402-341-0710 or mjbarnett@worldnet.att.net).

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