

polio network news

Research reports

NAPPS Preliminary Data

Pyridostigmine was not found to provide significant benefits with respect to quality of life, fatigue, or isometric muscle strength compared with placebo, although a trend was noted towards increased strength in very weak muscles.

NAPPS?

The North American Post-Poliomyelitis Pyridostigmine Study (NAPPS) received support from ICN Pharmaceuticals, the company that markets and distributes pyridostigmine as Mestinon. Currently approved for the treatment of myasthenia gravis, Mestinon is an oral anticholinesterase agent which improves the transmission of impulses across the neuromuscular junction, the interface of nerve and muscle cells.

NAPPS was initiated by participating investigators in five medical centers in the United States and Canada: Neil R. Cashman, MD and Daria A. Trojan, MD, Montreal Neurological Institute and Hospital, Montreal, Quebec, Canada; Burk Jubelt, MD, SUNY Health Science Center, Syracuse, New York; James Agre, MD, PhD, University of Wisconsin at Madison; Theodore L. Munsat, MD and Dave Hollander, MD, New England Medical Center, Boston, Massachusetts; and Robert Miller, MD, California Pacific Medical Center, San Francisco.

Conducted during 1996-97, NAPPS was a double-blind,

randomized, placebo-controlled trial that followed 126 patients given either 60 mg of pyridostigmine three times daily or placebo for six months; 64 received pyridostigmine and 62 received placebo. All participants completed the study.

RESULTS

During the six-month course of the study, 70 percent of patients on pyridostigmine and 73 percent of patients on placebo had at least eighty percent compliance with the medication. The study medication was well tolerated: four severe adverse events were observed during the trial, three of which occurred in pyridostigmine-treated patients. Some relative contraindications to pyridostigmine include certain cardiac arrhythmias, increased bronchial secretions and reactivity, and some urological disorders.

The study did not show a difference between pyridostigmine and placebo patients in terms of their health-related quality of life, fatigue, (as measured by two fatigue scales), and most measures of isometric muscle strength.

Health-related quality of life was assessed with the short form health survey — 36 (SF-36). Fatigue was measured with two subjective fatigue scales: the fatigue severity scale and the Hare fatigue symptom scale. Muscle strength was measured as isometric strength in twelve muscle groups in each patient by a modified Tufts quantitative neuromuscular exam.

Dr. Trojan, who presented at the annual meeting of the American Academy of Physical Medicine and Rehabilitation (AAPM&R) in Atlanta in November, noted that there was a nonsignificant increase in strength in very weak muscles (1% to 25% of predicted normal strength) in pyridostigmine-treated patients at six months of treatment.

Dr. Trojan also commented that the results were unexpected and did not reflect the investigators' clinical impression that there appeared to be a clear benefit in some patients.

Another purpose of the study was to assess the effect of Mestinon on IGF-1 (insulin-like growth factor-1) which is believed to support the sprouting of motor neurons. IGF-1 is known to decrease with age and may be a contributing factor to the onset of post-polio syndrome.

IGF-1 serum analyses have not yet been completed. Data analysis for the trial is still ongoing. The open trial phase of the study is still in progress. Therefore, this is not "the last word" on the study. We expect the NAPPS trial to be submitted for publication in the next few months.

CONTINUED ON PAGE 2

inside this issue ...

Post-polio Bibliography	3
The Netherlands	4
Italy	5
Nutrition and Post-polio	6

ICN Pharmaceuticals has no plans to fund further research into the use of Mestinon for post-polio fatigue. During these few years of affiliation, considerable literature aimed at educating health professionals has been created under the auspices of the Post-Polio Task Force, supported by an unrestricted educational grant from ICN Pharmaceuticals (See *Polio Network News*, Vol. 13, No. 3).

Information from the Post-Polio Task Force is available at www.post-polio.org. ■

international polio network

Polio Network News (ISSN 1066-5331)
Winter 1998 ■ Vol. 14, No. 1

Polio Network News is an international newsletter for polio survivors, health professionals, and resource centers to exchange information, encourage research, and promote networking among the post-polio community.

ISSUED QUARTERLY

International Polio Network (IPN)
4207 Lindell Boulevard, #110
Saint Louis, MO (Missouri)
63108-2915 USA

314/534-0475 ■ 314/534-5070 fax
Relay MO: 800/735-2966 TDD, 2466 V
gini_intl@msn.com

COORDINATED AND PUBLISHED BY:
Gazette International Networking
Institute (GINI)

EDITOR: Joan L. Headley, Executive Director
GRAPHICS: Sheryl R. Prater

Special thanks to:

Ellen Fay Peak, volunteer editor;
Lauro S. Halstead, MD; Daria Trojan, MD;
and Marianne Weiss, MS, PT

Annual subscription:

USA: \$20 ■ Canada, Mexico, and
Overseas surface: \$25 (US dollars only)
Overseas air: \$30 (US dollars only)

Copyright ©1998 by Gazette International
Networking Institute (GINI)

**Permission to reprint portions must be
obtained from the Editor.**

Research reports

Static Magnet Fields: Their Effect in the Control of Pain in Disabled Patients

The following is a summary of a poster presentation at the November 1997 meeting of the American Academy of Physical Medicine & Rehabilitation by Carlos Vallbona, MD (Baylor College of Medicine/Veterans Affairs Medical Center, Houston, Texas); Carlton F. Hazlewood, PhD; Gabor Jurida, MD.

Acute and chronic pain due to myofasciitis or degenerative joint disease may interfere with the rehabilitation of patients with disabilities. Analgesics and physical therapy are useful in pain management, but not always successful. We demonstrated the effectiveness of magnetic fields in a double-blind randomized clinical trial involving 50 patients with post-polio syndrome who reported muscular or arthritic-type of pain. The placement of a magnet that delivered a static field of 300 to 500 Gauss over a clearly identified trigger point relieved the pain rapidly and the effect lasted for some time after removal of the device. We have used similar magnets in other disabilities with good results. There is abundant literature on the biologic effects of magnetic fields, but the exact mechanisms of pain relief have not been elucidated. There may be a direct effect on pain receptors and/or an indirect change in perception due to the release of enkephalins in the reticular system. Specific issues that must be explored are: (1) dose response; (2) duration of effect; (3) synchronous response to magnets placed

on several areas; (4) differences of effect of various sizes and shapes of the magnetized device; and (5) cost effectiveness of pain management with magnetic fields.

Vallbona and colleagues' study of magnetic therapy in post-polio was also recently published.

Vallbona, C., Hazlewood, C., Jurida, G. (1997). Response of pain to static magnetic fields in post-polio patients: a double-blind pilot study. *Archives of Physical Medicine & Rehabilitation*, 78, 1200-1203.

Carlos Vallbona, MD, professor of family and community medicine and physical medicine and rehabilitation at Baylor and director of the Post-Polio Clinic at The Institute for Rehabilitation and Research (TIRR), and colleagues evaluated magnet therapy in adults diagnosed with post-polio syndrome who were experiencing arthritic pain in the joints or had identifiable points of pain in their muscles.

Thirty-nine women and eleven men participated in the study. Most were in their 50s and had developed post-polio syndrome during their 40s.

All patients were asked to press on the "trigger point" where they felt the severest pain and rank that pain on a scale of one to 10, with 10 being the worst. The patients were then randomly given an active or inactive magnet to strap against their trigger point for 45 minutes. After the magnets were removed, patients rated the intensity of their pain again.

Twenty-nine participants received an active magnet. Their average score of pain was 9.6 before the treatment, and 4.4 after wearing the magnet. The placebo group had an average pain score of 9.5 before treatment, and 8.4 afterward.

The low-intensity magnets, less than a half-inch thick and slightly stronger than refrigerator magnets, were available in four formats to accommodate different areas of the body: a credit-card-size rectangle, a six-inch strip almost two inches wide, a disc the size of a silver dollar, and a disc the size of a CD.

Seventy-six percent of the patients who had the active magnet reported a decrease in pain, but only 19 percent of the patients treated with a placebo felt an improvement.

International Polio Network has received several phone calls and letters from suppliers of magnets since the release of this data. The list includes:

MAGNAFLEX INC. (BIOflex products), 3370 NE 5th Avenue, Oakland Park, FL (Florida) 33334 (954/565-8500)

MAGNETHERAPY, INC. (Tectonic products) 950 Congress Avenue, Riviera Beach, FL (Florida) 33404 (561/882-0092, tectonic@slinet.com)

NIKKEN, one of the largest network marketing companies in the world, has its U.S. headquarters in Irvine, California. To find an independent distributor call, toll-free, 888/2-NIKKEN (888/264-5536).

NATURE SLEEP SYSTEMS, Magnet-X, #8 2180 Pegasus Way NE, Calgary, Alberta, Canada T2E 8M5 (403/291-3090, 800/667-0000, nss@nssbed.com, www.nssbed.com)

ENVIROTECH PRODUCTS, 17171 SE 29th Street, Choctaw, OK (Oklahoma) 73020 (405/390-3499)

MEDICAL MAGNETICS OF HOUSTON, P.O. Box 2941, Spring, TX (Texas) 77383-2941 (713/524-2220)

The Baylor/TIRR study consisted of one treatment per patient and did not evaluate how long the reported pain relief lasted. Vallbona suggests more research is needed to determine whether magnet therapy should be

recommended as an alternative to the standard treatments for pain in post-polio patients, such as physical therapy, support braces, anti-inflammatory drugs, and other medication. ■

Post-Polio Bibliography

Agre, J., Rodriquez, A., Franke, T., Swiggum, E., Harmon, R., Curt, J. (1996). Low-intensity, alternate-day exercise improves muscle performance without apparent adverse effect in post-polio patients. *American Journal of Physical Medicine & Rehabilitation*, 75 (1), 50-58.

The purpose of this study was to assess the effect of a twelve-week, low intensity, alternate-day exercise in 12 post-polio patients. The subjects performed six to ten knee extension exercises every other day. All subjects had greater than anti-gravity strength in the knee extensor muscles. Ankle weights were worn and gradually increased over the twelve-week period. After 12 weeks, the amount of weight lifted increased by over 50% on the average. There was no evidence of damage to the motor units by electromyographic assessment (single fiber EMG and macro EMG). There was no evidence of muscle damage by serial determination of creatine kinase (which is known to increase when muscle is damaged.)

JAMES C. AGRE, MD, PHD, WOODRUFF, WISCONSIN

Agre, J., Rodriquez, A., Franke, T. (1997). Strength, endurance, and work capacity after muscle strengthening exercise in postpolio subjects. *Archives of Physical Medicine & Rehabilitation*, 78, 681-685.

The purpose of this study was to assess the effect of a higher-intensity, four days per week, 12-week exercise program in seven of the ten previous subjects. (Five of the previous subjects could not participate due to such factors as time constraints.) Twice per week the subjects performed a series of isometric knee exterior exercises and twice per week a series of knee extensor

exercises with ankle weights. After 12 weeks, isometric muscle strength increased by over 30% on the average. Endurance and work capacity of the muscle increased by approximately 20% on the average. And there was no evidence of muscle damage or motor unit damage by creatine kinase and electromyographic determination, respectively.

Both studies have demonstrated increased strength with supervised exercise with no apparent evidence of damage. This is encouraging, however post-polio individuals should not interpret this research as carte blanche to exercise. To start an exercise program, consult with a knowledgeable physician.

JAMES C. AGRE, MD, PHD, WOODRUFF, WISCONSIN

Creange, S., and Bruno, R. (1997). Compliance with treatment for post-polio sequelae. *American Journal of Physical Medicine & Rehabilitation*, 76 (5), 378-382.

Polio individuals (204) evaluated by the Post-Polio Service at Kessler Institute for Rehabilitation were mailed anonymous surveys measuring Type A behavior, self-concept, and loneliness, to study their effect on completion of and compliance with a treatment program. Wheelchair use was associated with loneliness; wheelchair and crutch use were associated with a poor self-concept; asking co-workers for assistance was associated with a good self-concept; a high Type A score was related to patients not taking two 15-minute breaks each day and with loneliness; and loneliness was associated with poor self-concept. Sixty-three % had completed the program while 37% had

CONTINUED ON PAGE 10

Polio and Post-polio in The Netherlands

The Past

Since 1924, doctors in The Netherlands have had to report poliomyelitis under the Law on Infectious Diseases. Most years the number of cases was relatively low, but some years showed peaks.

Peak Years	Reported Cases	Number per 100,000 Population
1943	1,931	212
1944	1,218	133
1952	1,713	165
1956	2,206	203

A number of these polio survivors fully recovered or were left with mild limitations. In most cases, they were able to achieve positions in society and to live productive lives, including those who have used appliances for years.

In 1957, the Salk vaccine was introduced as part of the National Vaccination Programme. For some years following, all children born after 1945 were vaccinated in a "catching-up" campaign. From then on, all babies were vaccinated within the programme. This is how, in the long run, the vaccination percentage of 96 was reached.

Unfortunately, polio occurs again in a small number of cases. This is typical for The Netherlands, where vaccination is not mandatory and where some of the Dutch population refuse vaccination on ideological grounds. These groups include the orthodox protestant religious community, and the anthroposophist (centering on man, not God), macrobiotic



(extremely restricted diet), and Christian Science movements.

In 1971, 1978, and 1992-93, a few minor epidemics occurred exclusively among people who had not been vaccinated, with 39, 110, and 71 cases respectively. In 1992, the poliovirus type 3 (not endemic) must have been imported, but the infection remained within the boundaries of religious communities living in contiguous areas. (People in The Bible Belt relate closely within their own group, having their own schools.) The virus came to a dead end in the well-vaccinated surroundings.

When comparing the age structure of this latest outbreak with the previous one, we see the average age rising each time:

Year	Average Age	Subgroup 20 Years+
1956	1-4 years	?
1971	5-9 years	5%
1978	10-14 years	24%
1992-93	20 years	46%

Also, in 1992-93, persons over the age of 20 experienced a greater loss of function than

VSN members: (standing, l to r) Dick Buringa, Aadje de Groot, Liesbeth Laman, and (sitting, l to r) Hetty Sanders, Quirien Klaversteijn, and Annemiek Reynders.

persons under age 20. In 1978, there were no statistically significant differences between these age groups.

The Present

The Princess Beatrix Fund has offered financial support to polio survivors since 1956, as support is not covered by social welfare. Psychological support was not available.

In 1980, one of our group read an article in *Rehabilitation Gazette* (Saint Louis, Missouri, USA) about new problems after polio. We contacted each other and were able to join VSN, The Dutch Association of Neuromuscular Disorders, an association for people experiencing various neurological diseases. (Each disease has its own support group.)

Cooperating with VSN and our support group, "Polio Out of the World" has been active for several years now. Counting among its

members a virologist, a neurologist, and a rehabilitation specialist, this committee initiates projects to assist in banishing polio worldwide by the year 2000.

One of the committee's projects was a conference which resulted in the publication of *Polio en de gevolgen*, a book which discusses medical topics of the acute phase including recovery, the eradication of the poliovirus, and the rehabilitation methods for the late effects of polio.

In 1988, we started up our post-polio support group of 50 members. In 1997, we numbered 650. The Netherlands has an estimated 13,000 polio survivors, many of whom have already been (or are likely to be) confronted with post-polio syndrome.

What are the aims of our post-polio support group?

TO PROVIDE INFORMATION ON POST-POLIO SYNDROME TO MEMBERS AND SURVIVORS — This information covers the phenomenon of post-polio syndrome, the medical consequences, the importance of changing one's way of life, and referrals and references to neurologists and rehabilitation specialists. Information is given in a brochure, a post-polio newsletter, and during an annual meeting of members, where experts speak and where members meet and get to know each other. We have set up discussion groups all over the country.

TO PROVIDE INFORMATION ON POST-POLIO SYNDROME TO THE MEDICAL COMMUNITY

— Even to this day polio survivors will meet with inadequate medical aid because some doctors do not take their problems seriously.

Prof. Dr. M. de Visser, a neurologist, and Dr. F. Nollet, a rehabilitation specialist, are favourable exceptions and serve as pioneers in the field of post-polio syndrome in The Netherlands. Together we are working at spreading information among doctors. They do so through publications and presentations for their colleagues. We urge our members to take medical information on their visits to physicians.

CONTINUED ON PAGE 11

Polio and Post-polio in Italy

*Luisa Arnaboldi Maggioni,
Mapello, Italy*

I am the National President of the Don Carlo Gnocchi Former Student Association, a group of more than 40,000 disabled Italians, including poliomyelitic people, who have been treated and educated in eleven boarding schools in Italy.

Between 1954 and 1974, polio survivors were hospitalized during the acute phase. Afterwards, a priest named Don Gnocchi founded boarding schools which were in the vanguard at the time. In these schools we underwent physiotherapy, psychotherapy, and studied so we could actively take our place in society.



Luisa Arnaboldi Maggioni and her husband, Decimo Maggioni

We have only recently learned of post-polio syndrome and many of us are experiencing the symptoms. We immediately sought to find out what other countries were doing and to examine and introduce this issue in Italy.

We sent nearly one thousand questionnaires and about 50% have been returned. These questionnaires have only partially been reviewed by several Italian specialists who work with the Don Carlo Gnocchi Foundation. However, we are considering opening a screening center in one of the rehabilitation centers of the Foundation in order to address everyone's rehabilitation needs.

We aim to deal with this new phase with serenity and to take advantage of all the advanced scientific data at our disposal today. ■

Contact: Luisa Arnaboldi Maggioni, Associazione Ex Allievi Don Carlo Gnocchi, C.P. 36 - 24030 Mapello, Italy, or Antonia Fumagalli Grisi, S. Croce 567/C, 30135 Venezia (Venice), Italy.

Nutrition and Post-Polio

Lauro S. Halstead, MD

National Rehabilitation Hospital, Washington, DC

SEVENTH INTERNATIONAL
POST-POLIO
AND
**INDEPENDENT
LIVING
CONFERENCE**
ST. LOUIS, MISSOURI, USA

This is the story of my personal journey to learn more about nutrition. The path I followed and what I discovered along the way are specific to my body, my nutritional needs, and my disability. Some of the principles I learned may apply to others, but the particulars relate only to me. I would no more recommend you follow my specific diet than I would urge you to take someone else's medication. If you want to change your eating habits, please do it under the guidance of a licensed nutritionist. That's what I did.

As it turned out, the nutritionist I worked with had a special interest in chronic disease, although she was unfamiliar with post-polio syndrome. Before going to her, I held what I considered was a traditional but "enlightened" view of nutrition. In other words, I was

eating the kind of diet typically recommended in the medical literature and by the experts for a 61-year-old male with my medical history. What I quickly discovered is that "enlightened" is not always smart.

When I was in residency training many years ago, I attended a lecture by an eminent nutritionist who said males should restrict their intake of "visible" eggs to one or two a month; so I reduced mine to maybe half a dozen a year. A short time later, I heard another well-known nutritionist say he was starting his newborn son on 2% milk; I switched that night from whole milk (3%) to low fat (2%), and over the years limited my intake to what I used with cereal.

Then there was the issue of girth control. In the interest of watching my weight, I tried to avoid snacks and sweets, except on special occasions. Fortunately, I don't have a very sweet tooth, so this adjustment was not all that difficult.

And so it went. Over the years, I cut out greasy foods, then lightly fried foods, and finally even lean, red meat. By the time I saw the nutritionist for my first appointment in February 1996, my diet consisted, more or less, of the following: for breakfast, one to two large glasses of orange juice, a bowl of raisin bran with milk and one banana; for lunch, a large tossed salad with low calorie dressing, a half-pint of lowfat yogurt and fresh fruit; and for supper, typically fish or chicken (with occasional red meat), vegetables, potato or pasta, and a salad.

I also drank a soft drink mid-morning and mid-afternoon most days and had a nightcap at bedtime, most evenings.

Sounds pretty healthy, right? That's what I thought, too, especially when I considered that my cholesterol was normal, my weight was essentially the same as when I graduated from college, and people in the cafeteria line never tired of saying, "Wow, that's a healthy lunch!"

Well, my nutritionist didn't agree. When I returned after the first week with a diary of everything I had eaten and the amounts, her comment was, "This is incredible," and she didn't mean it as a compliment.

As it turned out, she thought almost everything I was doing was wrong. The bananas and orange juice were "empty" calories, the soft drinks were a sugar fix, and my lunch was skimpy at best. In short, I was on a starvation diet, in her opinion, which she calculated at 1300-1500 calories per day.

Well, if that were true, I asked, why wasn't I losing weight? Her explanation was that the body makes certain metabolic adjustments to accommodate different caloric intakes.

But it wasn't the caloric intake that bothered her so much. My biggest sin was the small amount of protein I was eating (about 5-6 ounces per day). "No wonder you're tired and weak. Anybody would be on that diet," she said. I, of course, thought instantly to myself, "Is this the cause of post-polio syndrome? Are we all just eating the wrong diet?"

The short answer is "no." But it's clear that a sensible diet can make you feel much better, as I was to find out fairly soon.

LAURO S. HALSTEAD, MD is Director of the Spinal Cord Injury Program and Director of the Post-Polio Program at the National Rehabilitation Hospital in Washington, DC. He is also Clinical Professor of Medicine at the Georgetown School of Medicine in Washington, DC. Dr. Halstead received his MD from the University of Rochester and a Master's in Public Health from Harvard University, where he took several courses in nutrition. He had polio in 1954 at the age of 18 and helped to organize the 1984 and 1986 Research Symposia on the Late Effects of Poliomyelitis in Warm Springs, Georgia.

FINDING NUTRITIONAL ADVICE ...

The main goals of my new nutritional plan were to increase the amount of protein, increase the number of calories, avoid the empty calories of orange juice and soft drinks, and finally, cut back on that nightcap.

While all of this was going on, I spent a fair amount of time at the library reviewing what's known about protein metabolism and what would be particularly relevant for polio survivors. Here's some of what I learned.

First, proteins are in all human cells. In fact, they form the basic building blocks for each cell, its metabolism, and life itself.

Second, proteins are made from amino acids, and new proteins are being made (synthesized) and broken down (degraded) each day. This protein turnover applies to muscle cells, as well, which are constantly synthesizing new protein every day. Some of this new protein comes from what we eat and some comes from "re-built" protein using amino acids already in the body.

The third thing I learned, and most important for persons with post-polio syndrome, the largest "consumer" of protein in the body is muscle.

All of this means that for the muscles to have a fighting chance to maintain or increase their strength, there has to be a generous amount of protein in the diet. We are not carnivores by chance.

Knowing this, I changed my views on meat and other protein in a jiffy. At the same time, I relaxed my attitude about calories, as well. In summary, I experienced a "nutritional makeover."

It has been almost a full year since my dietary epiphany. I now eat lean meat regularly, along with nuts, fish, eggs, oatmeal, and anything else with protein. I don't eat

fruit for snacks as much, and most days, instead of a soft drink, I drink a home brew fortified with a protein supplement.

The results? My daily intake of protein has more than doubled to at least 12 ounces per day and my total calories are now somewhere between 1800-2000 per day. My weight is essentially unchanged. The best part is that my "good" arm, which used to be tired all the time, feels stronger, gets less fatigued at the end of the day, and seems to recover faster when it gets overworked.

Is this a "cure-all?" Absolutely not. I estimate my improvement in the 2-5% range, but it hasn't impacted all of my symptoms. I still get intense fatigue in the afternoon. My tank of gas is totally depleted by the end of the week. I'm still searching for new ways to pace myself to conserve what energy I have. Is my new diet healthier living through healthier eating? I believe so. Will it work for others? I don't know. What I have learned for sure, is that sensible eating under the guidance of an experienced nutritionist, is good advice for everyone. ■

The Certification Board for Nutrition Specialists certifies advanced degree nutritionists. For a listing of certified nutritionists in your state, write: Certification Board for Nutrition Specialists, Hospital for Joint Diseases, 301 East 17th Street, New York, NY (New York) 10003.

The American Board of Nutrition (ABN) establishes standards in the field of clinical and human nutrition. A Specialist in Human Nutrition has an educational background in a biological science and has earned a PhD or equivalent. A Specialist in Clinical Nutrition has an MD or DO degree and is licensed to practice medicine. Both have passed an examination given by the Directors of the ABN.

A registered dietitian (RD) has completed a minimum of four years of education and training in dietetics or a related area and has passed a credentialing examination.

The National Center for Nutrition and Dietetics (NCND) provides direct access to food and nutrition information. Call 800/366-1655 (10:00 a.m. - 5:00 p.m. EST) to receive a referral to an RD. Call 900/CALL-AN-RD (900/225-5267) for personalized answers to food and nutrition questions from registered dietitians. Calls are \$1.95 for the first minute and \$.95 for each additional minute. Additional information may be found at the web site of The American Dietetic Association (ADA) Foundation (www.eatright.org).

A Guide to Daily Food Choices FROM THE U.S. DEPARTMENT OF AGRICULTURE

FOOD GROUP	A SERVING IS ...	NO. SERVINGS
<i>Milk, yogurt, & cheese group</i>	1 cup milk, 1/2 cup ice cream, 1 cup yogurt, 1 1/2 oz. cheese (1 1/2 to 2 slices)	2-3
<i>Meat, poultry, fish, dry beans, eggs, & nuts group</i>	2-3 oz. cooked, lean meat, 1 egg, 2 tbsp. peanut butter	2-3
<i>Vegetable group</i>	3/4 cup juice, 1 potato, 1/2 cup raw or cooked vegetables	3-5
<i>Fruit group</i>	3/4 cup juice, 1 medium fruit	2-4
<i>Bread, cereal, rice, & pasta group</i>	1 slice bread, 1/2 bagel or hamburger bun, 1/2 cup pasta or rice or cooked cereal	6-11

Gait and Post-Polio

Marianne Weiss, MS, PT

Wheeling Jesuit University, Wheeling, West Virginia

Falls are a chief cause of death and increased disability in this country. Among the physical problems leading to falls are loss of balance, overall fatigue, repetitive motion leading to individual muscle fatigue, weak muscles, and abnormalities in gait.¹ Many polio survivors exhibit one or more of these problems. Using assistive devices for walking can reduce the severity of these abnormalities or reduce the effect that they have on the lives of polio survivors.

Some survivors have used assistive gait devices for many years. Others used them only in the acute stage of recovery after polio, while others never used them. How do you know if you need an assistive device for walking or if you need to change the one you have?

MARIANNE T. WEISS, MS, PT

has been practicing physical therapy for 20 years. She holds a BS in Allied Health Professions (physical therapy) from The Ohio State University and a post-professional MS in physical therapy from the University of Indianapolis. She has experience working in many settings including hospitals, nursing homes, home health agencies, and private practices. She has directed a physical therapist assistant educational program, and she currently is an assistant professor of physical therapy at Wheeling Jesuit University in Wheeling, West Virginia. She has treated polio survivors since 1982.

Some signs that can help you answer those questions are these: lessening endurance for walking due to muscle fatigue, worsening of a limp, pain in the legs during walking, a history of falls, or the recent occurrence of new falls.² If you suspect that you need an assistive device in walking or a new type, discuss the matter with your doctor, who will probably refer you to a physical therapist for an evaluation.

The therapist will then assess: how your strength and flexibility affect your ability to walk and to get up and down from a seated position; whether you have enough upper body strength and flexibility to safely and effectively use an assistive device; how good your balance is³; and how your heart and lungs react to walking. In many cases, the use of an assistive device reduces the strain on the heart and lungs because the device uses less energy than, for example, the limp it corrects. However, in some cases, using an assistive device may be more taxing on the heart and lungs than walking without a device.⁴ If this is the case, the assistive device that the therapist recommends may be an electric scooter or motorized wheelchair.

Finding an appropriate assistive device for walking for polio survivors can be a challenge. If a person has a one-sided problem in the legs, usually a one-sided device, such as a cane or a single crutch, is indicated (most often used in the hand *opposite* the affected leg). However, abnormalities of strength, pain, or flexibility in the arms may make using a one-sided device impossible.

Similarly, problems in the arms may make using two-sided devices such as walkers, two crutches, or two canes difficult, if not impossible. The trick is to find the device that provides enough assistance to compensate for the physical abnormality without causing other physical problems.

Sometimes the evaluation reveals too much disability for the survivor to benefit from an assistive gait device. This finding can free the survivor to make the decision to walk only in the home and to use motorized conveyances to move about in the community. Many who become motorized are pleasantly surprised to find how easily they can participate in community activities again and how much more energy they have after they make the decision to ride rather than walk outside their homes.

If the evaluation reveals that an assistive device would improve your gait, the therapist will recommend a specific device, assist you in obtaining it, fit it to you, teach you how to use it, and assess its effectiveness in meeting the goal for which it was recommended. Frequently the therapist may also recommend a *gentle* exercise program of strengthening and stretching to further assist your walking efforts. Certain types of braces or splints may also be recommended.^{5,6}

In working with polio survivors for the last 15 years, I have seen many of them helped significantly by their using appropriate assistive devices for walking. The devices can help reduce pain and fatigue and reduce limping. And, of course, all of this leads to a reduction in the incidence of falls — resulting in less chance of more serious disability or even premature death.

So, what are you waiting for? If you think an assistive device might make your life easier, start the process described above by obtaining your physician's opinion. ■

References

1. Shumway-Cook A. and Woolacott M. (1995). *Motor control, theory and applications*. Philadelphia: Williams and Wilkins.
2. Pierson F. (1994). *Principles and techniques of patient care*. Philadelphia: Williams and Wilkins.
3. Minor MA and Minor SD. (1995). *Patient care skills*. Norwalk, CT: Appleton and Lange.
4. Perry J. (1992). *Gait analysis*. Thorofare, NJ: Slack, Inc.
5. Smith LK and Mabry M. (1995). *Polio-myelitis and the post polio syndrome*. In Umphred D (Ed.), *Neurological rehabilitation*. 3rd ed. Philadelphia: Mosby.
6. O'Sullivan SB and Schmitz TJ. (1995). *Physical rehabilitation: assessment and treatment*. 3rd ed. Philadelphia: FA Davis.

readers respond

From *Polio Network News*,
Volume 13, No. 3:

"Can anyone offer suggestions as to which is the best car to purchase for putting a wheelchair in the back seat?"

Ed, Missouri

"We like our '93 Plymouth Vista made by Mitsubishi, sold by Plymouth dealers as Vista and Eagle Summit. It is a mini mini-van looking vehicle with all-wheel drive and a low loading height. The wheelchair stands upright behind the rear seat. Unfortunately, the last year of importation was 1996. You may be able to find an older model still with the guarantee."

Paul, New York

"Most people think that they should buy a four-door car, however, a two-door works much better because the door opens wider and is 'out of the way' as you put your wheelchair in the back seat."

Carolyn, Florida

"As of 1996, the only ones that have that option are GM cars. Call your GM dealer or the GM Mobility Assistance Hotline at 800/323-9935.

"Another option is to buy a four-door car with a bench or split front seat and put the chair in a car-top carrier on the roof. Whoever installs hand controls, etc. in your area would have that information."

Alice, Ohio

Resources

For a free, state-specific information packet and details about the GM Mobility reimbursement program, contact: GM Mobility Assistance Center, P.O. Box 9011, Detroit, MI (Michigan) 48202 (800/323-9935 voice, 800/833-9935 TTY, or 313/974-4383 fax).

According to the GM literature, several two-door models of Chevrolet and Pontiac and a fewer number of two-door models of Buick, Geo, Oldsmobile, and Cadillac can accommodate a typical adult folding wheelchair in either the back seat or trunk. Numerous four-door models can accommodate the wheelchair in the trunk only. They also provide a listing of vans and light trucks which are wheelchair and electric scooter compatible.

The GM Mobility Assistance Program offers financial reimbursement (up to \$1,000) towards adaptations on new and unused vehicles. Contact them for details including mobility equipment installers, driver assessment facilities, state rehabilitation services, and driver licensing offices, etc.

For similar information, contact Ford Mobility Motoring Program Headquarters, P.O. Box 529, Bloomfield Hills, MI (Michigan) 48303-9857 (800/952-2248), or Chrysler Corporation's Auto-mobility Program Headquarters, P.O. Box 3124, Bloomfield Hills, MI (Michigan) 48302-3124 (800/255-9877 voice, 800/922-3826 TTY, or www.automobility.chrysler.com).

For "designer" canes and walking sticks, contact:

The Harris Company

Penny and Bob Harris
29 Dennison Avenue,
Swampscott, MA (Massachusetts)
01907 (Jan-May) or
(May-Dec) 16040 Loch Katrine Trail,
#7805, Delray Beach, FL (Florida)
33446

Contact them at 800/943-5646, access 41 or www.walkingstick.com.

Prompted by his wife's wish to have more fashionable crutches during her recuperation from hip surgery, "retired" women's shoe designer Bob Harris decorated a pair with red-white-and-blue bunting. When then First Lady Barbara Bush broke her leg, Bob sent a decorated pair to her, which resulted in a story printed in *The Boston Globe*. Thus began a new career for the designer, who now creates handcrafted canes of selected woods and finishes, also available in a wide variety of scotch-guarded fabrics and coverings.

House of Canes

Mailing Address: P.O. Box 574,
Shipping Address: 767 Old Onion Mt.
Road, Wilderville, OR (Oregon) 97543
(541/476-4094, 541/955-8820 fax, or
kay@houseofcanes.com)

Mark Fontaine has made over 18,000 canes in 18 years. The single point wooden cane with the off-set T or Derby handle is his specialty, but other shaped handles and even ready-made canes are available.

For "designer" crutches and other walking aids, contact:

Walk Easy, Inc.

2915 South Congress Avenue,
Delray Beach, FL (Florida) 33445
(800/441-2904)

Walk Easy carries a full line of modern, lightweight walking aids including forearm and underarm crutches. Colors include blue, bronze, green, black, purple, white, yellow, several "neons," and several pastels.

either been discharged for non-compliance or for refusing treatment. These latter individuals had a 5% increase in fatigue and a 60% increase in muscle weakness an average of 16 months after evaluation.

No individual therapeutic recommendation (assistive device use, resting, pacing, or requesting physical assistance from others) was significantly related to a reduction in symptoms, suggesting that multiple lifestyle changes should be implemented. Importantly, compliance has less to do with patients' self-acceptance than with their sense of being accepted by others. Friends and family members can help polio survivors accept lifestyle changes and support the use of new assistive devices.

RICHARD L. BRUNO, PhD, ENGLEWOOD, NEW JERSEY

Grimby, G., Kvist, H., Grangard, U. (1996). Reduction in thigh muscle cross-sectional area and strength in a 4-year follow-up in late polio. *Archives of Physical Medicine & Rehabilitation*, 77, 1044-1048.

This study demonstrated that the cross-section area of thigh muscles was reduced significantly in post-polio survivors, who reported reduced muscle weakness during the last four years. Also the total thigh muscle strength decreased during that period. The reduction in strength was greater than the reduction in the cross-sectional

area. The results demonstrate not only progress of muscle weakness, but also muscle atrophy in post-polio survivors.

GUNNAR GRIMBY, MD, PhD, GÖTEBORG, SWEDEN

Ernstoff, B., Wetterqvist, H., Kvist, H., Grimby, G. (1996). Endurance training effect on individuals with postpolio-myelitis. *Archives of Physical Medicine & Rehabilitation*, 77, 843-848.

The results of a six-month combined endurance and strength training program in 17 post-polio subjects in the ages from 39-49 years are reported. All were walkers. Strength increased in some muscle groups. Exercise performance on the bicycle ergometer increased. The training program could be performed without major complications and was perceived positively. Careful individual monitoring by clinical observations is necessary in physical training of post-polio persons.

GUNNAR GRIMBY, MD, PhD, GÖTEBORG, SWEDEN

Kralingen, K., Ivanyi, B., van Keimpema, A., Venmans, B., deVisser, M., Postmus, P. (1996). Sleep complaints in postpolio syndrome. *Archives of Physical Medicine & Rehabilitation*, 77, 609-611.

Kemp, B., Adams, B., Campbell, M. (1997). Depression and life satisfaction in aging polio survivors versus age-matched controls: relation to postpolio syndrome, family functioning, and attitude toward disability. *Archives of Physical Medicine & Rehabilitation*, 78, 187-192.

Nordgren, B., Falck, B., Stålberg, E., Ronquist, G., Waldenström, A., Ahlström, H., Hemmingsson, A. (1997). Postpolio muscular dysfunction: relationships between muscle energy metabolism, subjective symptoms, magnetic resonance imaging, electromyography, and muscle strength. *Muscle & Nerve*, 20, 1341-1351.

Schanke, A. (1997). Psychological distress, social support and coping behaviour among polio survivors: a 5-year perspective on 63 polio patients. *Disability and Rehabilitation* 19 (3), 108-116.

Thorsteinsson, G. (1997). Management of postpolio syndrome. *Mayo Clinic Proceedings*, 72, 627-638.

Honors received

Canada — Canada was the recipient of the Franklin Delano Roosevelt International Disability Award for 1997. It is presented annually to a nation that makes noteworthy progress toward fulfilling the United Nations World Programme of Action Concerning Disabled Persons.

Canada was recognized for its implementation of laws which protect people with disabilities from discrimination, its Employment Equity Act, and Canada's National

Strategy, a \$158 million program guided by people with disabilities, which funded hundreds of projects to improve access to housing, employment, transportation, education, and communications. Canada also was commended for its leadership in the development and signing of the international landmine treaty.

Justin Dart — Known as the father of the ADA (Americans with Disabilities Act), Justin Dart, Jr. was one of 15 Americans honored by President Bill Clinton with the Presidential Medal of Freedom, the highest award given to civilians. In bestowing the awards, Clinton

acknowledged their individual efforts in helping "America to widen the circle of democracy by fighting for human rights, by righting social wrongs, by empowering others to achieve ..."

Dart, who began his civil rights activities more than forty years ago, dedicated his award to people with and without disabilities across the country who work on behalf of people with disabilities.

The March 1998 issue of *Mainstream Magazine* features "Justin Dart, Jr., Soldier for Empowerment." The special section on this legendary polio survivor

We have sent mailings to all general practitioners, neurologists, and rehabilitation specialists in the country. So far, this information appears to have primarily influenced the rehabilitation specialists. The general practitioners fail to be very interested, partly due to the fact that they rarely see a person with or who had polio.

VSN operates a documentation centre on the late effects of polio, accessible to (para)medical persons and members. Last but not least, VSN encourages scientific research. Our support group actively promotes research on post-polio syndrome with The Princess Beatrix Fund providing the necessary funds.

TO PROVIDE INFORMATION ON POST-POLIO SYNDROME TO OTHERS —

Society in general has little knowledge and understanding of the late effects of polio ... "What are you talking about?" ... "Polio is past tense." Many of these persons are often unaware of the phenomenon of post-polio syndrome. We aim to educate, among others, the executors of social legislation and the medical examiners dealing with the

requests for partial work or full-time disability.

The Future

As a post-polio support group, we have a goal of a time when we shall have a well-functioning national medical centre, where all knowledge about the problems of polio and its late effects is concentrated. We hope that some day neurologists and rehabilitation specialists will work together with physiotherapists, ergotherapists, and social workers in order to help those who come with questions and concerns.

We are also planning a translation into English of *Polio en de gevolgen*, so it can be distributed in other European countries. This might lead to improved interaction between European post-polio organizations, a European conference on post-polio syndrome, and a stronger European post-polio network. ■

Contact: VSN, Post-polio Support Group, Mrs. Quirien Klaversteijn, Secretary, Hoenderkopershoek 31, 3981 TD Bunnik, The Netherlands.



in the disability rights movement covers his birth through his emergence as a leader for disability rights.

Since 1975, *Mainstream* has published a national disability and advocacy news and lifestyle magazine that features new products and technology, education, employment, travel and recreation, and provocative commentary.

One-year subscription (10 issues) for \$24; 2 years for \$44; available on computer disk (ASCII). Contact: *Mainstream Magazine*, 2973 Beech Street, San Diego, CA 92102 (619/234-3138 or www.mainstream-mag.com). ■

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.

1998

New Options in Management of Post-Polio Syndrome, APRIL 25, Blue Heron Pines Golf Club, Cologne, New Jersey. Contact: Jack Martin, PT (609/748-5429 or 609/652-9581 fax) or Linda Feinstein (609/383-1273, LynFein@aol.com).

Nothing Can Stop Us Now, MAY 1-3, Sheraton Perimeter Park South Hotel, Birmingham, Alabama. Contact: Wanda Merrill, 717 Rockhurst Drive, Birmingham, AL (Alabama) 35209-3170 (205/290-9477, 205/945-8541 fax, or comquate@aol.com).

Future Approaches for Polio Survivors, AUGUST 28-29, Holiday Inn/Northglenn (a suburb of Denver). Contact: Mary Ann Hamilton, 1185 S. Williams Street, Denver, CO (Colorado) 80210 (303/722-6945, 303/722-7386 fax, or hamil1185@aol.com).

Seminar for polio survivors and caregivers, OCTOBER 10, Las Vegas, Nevada. Contact: Caroleanne Green, National Polio Care Advocates, 741 Gullwing Lane, North Las Vegas, NV (Nevada) 89031 (702/649-9361, 702/649-6824 fax, or send LSASE for packet (no registration fee)).

International Polio Congress and Industrial Exhibition, OCTOBER 30-31, Jena/Thuringia, Germany. Contact: Bundesverband Poliomyelitis e.V. c/o Hendrich, Thastr. 27, D-35392 Giessen, Germany (+49/30/805-3593; +49/30/8060-2251 fax, www.members.aol.com/poliomed/ or WEFMurach@aol.com).

Disability on the Air

BEYOND AFFLICTION: The Disability History Project

A series of four one-hour programs distributed by NPR®

Straight Ahead Pictures and National Public Radio® have announced *Beyond Affliction: The Disability History Project*. Laurie Block, series' creator, host, and producer, will uncover the common history shared by people with the full spectrum of disabilities and their families since the Civil War and tell the story of disability in the United States in an historical context. NPR's "Talk of the Nation" will broadcast related coverage, part of which will be hosted by John Hockenberry.

As the name suggests, *Beyond Affliction* aims to move the general public beyond the "affliction myth" and into a more authentic perception of the disability community's reality, past and present. *Beyond Affliction: The Disability History Project*, produced by Block and Jay Allison, is scheduled for broadcast on NPR in May 1998. Check local listings for details.

Generous underwriting support for *Beyond Affliction* comes from the Corporation for Public Broadcasting, AT&T, Massachusetts Foundation for the Humanities, and the California Council for the Humanities.

For information contact: Tari Susan Hartman at EIN SOF Communications (310/578-5955, 310/578-6065 fax, EINSOFTSH@aol.com; or Marge Ostroushko (612/287-8686 phone, 612/287-8757 fax or most@well.com).

LIVING WITHOUT LIMITS™

Developed by Dr. Bob Enteen, LIVING WITHOUT LIMITS™ was recently awarded funding by The Robert Wood Johnson Foundation and the National Multiple Sclerosis Society. LIVING WITHOUT LIMITS™ is a half-hour interview program taped at the NPR studios in New York and Washington, DC, and is currently broadcast on more than 25 stations across the country. Included in the station line-up are community, university, and hospital stations, and subscribing stations of the Radio Reading Services.

For information on airing LIVING WITHOUT LIMITS™ locally, contact Bill Rosen at the National MS Society, 733 Third Avenue, New York, NY (New York) 10017-3288 (Rosen@NMSS.org or call 212/476-0462.)

Note to Readers

IPN's continued networking efforts has resulted in an increase in requests for our involvement in research projects. Many investigators need 'subjects' or polio survivors or you. Our policy is not to give them your name, but to act as intermediary sending you the information, allowing you to respond or not.

If you do not want to periodically receive information to participate in a variety of research efforts (medical, sociological, psychological, etc.), contact IPN.

A PARALYZING FEAR: THE STORY OF POLIO IN AMERICA

PBS Release, Fall 1998

The theatrical release of *A Paralyzing Fear: The Story of Polio in America* is scheduled for March at the Film Forum in New York. The exact date of airing on PBS is not known, but readers should check the local PBS programming schedule in September. A companion book will also be available.

The 90-minute documentary film follows polio from illness to epidemic to the development of the vaccine and is dominated by engaging, archival film. The documentary addresses the effects of the "polio scare" on the American people by featuring polio survivors, their families, doctors, nurses, scientists, and journalists who were directly impacted by polio.

Each segment is introduced by pertinent quotations and photographs followed by well-chosen remembrances from recent interviews. The interviews, archival film, and photographs are connected by a fact-packed script delivered by actress Olympia Dukakis.

The film, written and directed by Nina Gilden Seavey, was funded by the National Endowment for the Humanities and the Corporation for Public Broadcasting.

The film will be available to groups wishing to show it prior to its running on PBS. For more information, contact: Nina Gilden Seavey, Center for History in the Media, George Washington University, 801 22nd Street, NW, Washington, DC 20052 (202/994-6787, 202/994-6231 fax, or SEAVEY@GWIS2.circ.gwu.edu).

**Gazette
International
Networking
Institute**

4207 Lindell Boulevard, #110
Saint Louis, MO 63108-2915 USA

Non-Profit Org.
U.S. Postage
PAID
St. Louis, MO
Permit No. 1711