

# Polio Network News

## The Role of Activity

James C. Agre, MD, PhD, Woodruff, Wisconsin

*“To exercise or not to exercise, that is not the question for polio survivors; rather, the questions are these: what amount of exercise is enough? what amount is too much?”*

There is no easy answer for all polio survivors, but we can make some general observations about inactivity and exercise.

### ADVERSE EFFECTS OF INACTIVITY

Limitation in physical activity results in progressive deterioration of cardiovascular performance and efficiency; metabolic disturbances; difficulty in maintaining normal body weight; disturbed sympathetic nervous system activity; reduction in muscular strength and endurance; and possibly emotional disturbances.

### BENEFICIAL EFFECTS OF REGULAR EXERCISE

In contrast, beneficial *physiologic* adaptations to regular exercise include reduction in heart rate and blood pressure; morphologic changes in skeletal and cardiac muscle resulting in improved physical work capacity and an enhancement of cardiovascular efficiency in delivering oxygen and nutrients to the tissues; increased muscular endurance; increased myocardial vascularity; reduced blood coagulability; reduction in adiposity and increased lean body mass; increased cellular sensitivity to insulin; and favorable changes in blood lipids and cholesterol.

Beneficial *psychological* changes from regular exercise include reduction in muscular tension;

improved sleep; and possible increased motivation for improving other health habits such as changes in diet (reduction in saturated fat consumption, for example) and cessation of cigarette smoking.

### EVIDENCE FOR BENEFICIAL EFFECTS OF EXERCISE IN POST-POLIO INDIVIDUALS

Studies have shown strengthening exercise, aerobic conditioning exercise, and ambulatory exercise to be beneficial.

*Strengthening Exercise* – In Feldman and Soskolne’s study of six post-polio patients, the subjects performed non-fatiguing exercise three times per week for 24 weeks or longer. Strength either increased or remained the same in all muscles in all subjects except for one muscle in one subject that became weaker. The authors concluded that the strengthening exercise was, in general, very beneficial.

Einarsson and Grimby studied 12 subjects who exercised three times per week for six weeks. The subjects performed intervals of strengthening exercise interspersed with rest breaks. All subjects became significantly stronger in the six-week period.

Fillyaw and colleagues studied 17 subjects who exercised every other day for up to two years. The exercise intervals were interspersed with rest breaks. Over this period of time, all subjects gained significant strength.

At the University of Wisconsin, we conducted a 12-week study of muscle-strengthening exercise in seven post-polio subjects. Subjects exercised four times per week for 12 weeks at home. Exercise intervals were interspersed with rest breaks. After the 12-week program, the average increase in strength was 36%; also work capacity and endurance increased by 15% or more.

*Aerobic and General Conditioning Exercise* – Four such studies have been performed. Jones and colleagues studied 37 post-polio subjects: 16 volunteered for the exercise program while 21 served as control subjects. The exercise subjects performed stationary bicycle exercise three times per week for 16 weeks. They began with bouts of exercise of 2-5 minutes on the bicycle with 1-minute rest breaks, progressing up to 15-30 minutes of exercise per session. After the program, the exercise subjects were found to have significant improvements in their aerobic power and their capacity to exercise. The control subjects did not change in this same time interval.

Kriz and colleagues performed a similar study in 20 post-polio sub-

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jects (with 10 exercise and 10 control subjects); however, the exercise was upper-limb cycle ergometry (rather than lower-limb cycle ergometry). In this study, too, exercise subjects significantly increased their aerobic power and exercise capacity.

Grimby and Einarsson studied 12 post-polio subjects who performed submaximal endurance and strength training twice weekly for six months. Activity was interspersed with rest breaks. Except for one, all subjects were significantly improved from the training program. The exception reported excessive fatigue with the training program. Grimby and Einarsson concluded that combined endurance training and submaximal strengthening exercise can be generally positive in post-polio individuals, but that overtraining can occur.

Prins and colleagues studied 13 post-polio subjects. Nine performed a swimming and aquatic strengthening exercise program and four were controls. Intervals of exercise were interspersed with intervals of rest. The authors reported significant improvements in strength and flexibility in the exercise subjects and no change in the control subjects.

**Ambulatory Efficiency** – Dean and Ross studied 20 post-polio subjects. Thirteen were control subjects and seven performed tread-

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mill walking exercise three times weekly for six weeks. The exercise was low-level, non-fatiguing, and not painful. After the six-week program, the exercise subjects walked more efficiently, while the control subjects showed no change. The study concluded that regular exercise could improve movement economy.

Exercise studies have shown that *judicious exercise* can improve muscle strength, range of motion, cardiorespiratory fitness, and efficiency of movement in some post-polio individuals. These benefits appear to occur when they keep their activity and exercise within reasonable limits to avoid excessive muscular fatigue or joint or muscle pain. Post-polio individuals should avoid activities that cause increasing muscle or joint pain or excessive fatigue, either during or after their exercise program because the performance of activity at too high a level may lead to overuse/overwork problems. ■

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In a study conducted in The Netherlands, PPS subjects ( $n = 76$ ) showed higher scores ( $p < .001$ ) than non-PPS subjects ( $n = 27$ ) within the NHP (Nottingham Health Profile) categories of physical mobility, energy, and pain. On a 16-item Polio Problems List, 78% of PPS subjects selected fatigue as their major problem, followed by walking outdoors (46%) and climbing stairs (41%). The disabilities of PPS subjects were mainly seen in physical and social functioning. No differences in manually tested

strength were found between patient groups. PPS subjects needed significantly more time for the performance test than non-PPS subjects and their perceived exertion was higher.

PPS subjects are more prone to fatigue and have more physical mobility problems than non-PPS subjects. In former polio patients, measurements of perceived health problems and performance tests are the most appropriate instruments for functional evaluation. ■

# To walk or not to walk ... that is the question?

Bruce Ellison, New South Wales, Australia

*"Tis it more noble in the mind to suffer the outrageous slips and falls of life, than to wheel in comfort?"*

This very parodied version of one of Shakespeare's better known passages from Hamlet, highlights one of the most important decisions a person with mobility difficulties will face.

In my experience, I have found that the timing of when to stop walking and perhaps go to what at first may seem a retrograde step, can be very frightening and quite tearful. Once taken, the decision seems to have been the right choice and one wonders what all the fuss was about.

To understand the problem fully, I feel one must look at our society's view of walking or not walking, as the case may be. The best way we can do this is to take a long view of mankind's rise from the primordial "soup" to become the unique species that stood on its hind legs and walked erect, like no other creature could do. Ever since that day, mankind has been trying to go as far as it can, in search of its destiny.

It was the way social coexistence began, as groups of like-minded creatures began to meet and form tribes, etc. Conflicts started as one group came across another and accepted one another, or fought, or moved on to an uninhabited area. Natural boundaries became important, as they stopped these tribes from walking too far from what was familiar.

Over time, the novelty of walking gave way to the training of animals to do the walking, hence riding a variety of animals such as

horses, oxen, donkeys, camels, elephants, llamas, alpacas, and even ostriches. But, this too had its drawbacks – comfort for one, skill and aptitude for another.

Hence, humankind's greatest invention ... the wheel. This revolutionised all thinking and broadened all horizons. It was not too long after that, or because of that, that the military implications of the wheel brought the development of roads to link various strategic tribal settlements and form towns. Civilisations started to rise and fall on their ability to use the wheel and move their armies about.

The Industrial Revolution saw the development of steam engines, which eventually saw the arrival of trains and the first large scale and efficient use of public transport. Travel was accomplished by people being seated in some luxury, thus creating the lifestyle of the modern man.

The twentieth century has seen this trend further developed with the arrival of the automobile and aeroplane. We now have a society that spends large amounts of time and money on the avoidance of walking, while travelling large distances which were unheard of in previous centuries.

As one can see, this practice creates a serious dilemma for people who feel they have to walk to stop the advances of progressive diseases such as muscular dystrophy. These individuals are placing themselves at physical risk of injury by trying to stay on their feet, when the rest of society is opting for the least amount of walking.

Is it worth the risk?

Wheelchair technology has advanced more rapidly than society's willingness to change its attitude to people with disabilities, and their need for modification of the built environment in order to participate in all aspects of life.

A life in a wheelchair is not easy, but the rewards can be considerable once you have taken the time to assess your quality of life.

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## International Polio Network

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Is the prospect of falling over at home or on the street something you would enjoy, just to make your ego happy? Does being ambulant give you and those that you love and care for, more or less independence?

The answers to these questions need to be carefully thought through. If the answer is "less independence," you should consider a life that includes some time in a wheelchair.

Some of the things to consider are:

- Can you rise from a chair easily without assistance?
- Can you use a street crossing without fear of falling over?
- Can you get more than halfway across a set of traffic lights before the DON'T WALK sign stops flashing?
- Can you climb a small flight of steps which has no handrail?
- Can you climb a larger flight of steps without feeling exhausted?
- Can you easily catch a bus or train? Can you easily get in and out of a car? Do you feel safe in the shower or bath?

This is not a definitive list, but a starting point.

To conclude, this question of when to stop walking shows that "swimming against the tide" of society in the long run only hurts "the swimmer," and society loses the opportunity of receiving our valuable input.

We need to be part of society, not apart from it just because we cannot walk. ■

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## The Changing Dynamics of Aging with Polio

Margaret L. Campbell, PhD, California State University-Los Angeles

"Aging with polio" refers to two interrelated phenomena. On a macro level, it refers to dramatic improvements in life expectancy, which are part of the "longevity revolution" that is simultaneously altering the landscape of aging and disability (Jones et al., 1997; Seelman & Sweeney, 1995). Thanks to recent advances in medical rehabilitation, emergency medicine, and consumer education, for the first time in history persons with significant disabilities, like their nondisabled counterparts before them, are surviving long enough to experience both the rewards and challenges of mid- to later-life (Ansello & Eustis, 1992). No where are the changing demographics of disability more evident than for persons aging with the long-term effects of polio. Estimates from the most recent National Health Interview Survey indicate that there are between 430,000 and 1,000,000 polio survivors alive today in the USA, and more than half of these individuals are 55 years of age or older (NHIS, 1994-95).

The changing dynamics of polio have not come without their "costs," however. In exchange for the personal benefits of increased longevity, many polio survivors, as they age into mid-life and beyond, experience the onset of new, and frequently unexpected, health problems and functional changes that threaten to erode independence and reduce quality of life (Maynard, Frchheimer, & Roller, 1991; Campbell, Kemp, & Brummel-Smith, 1994). Clinicians treating polio survivors were some of the first to call attention to the health problems associated with long-term disability (Maynard, 1981; Halstead, 1985). Since the

early 1980s, their primary focus has been on the cluster of new polio-related symptoms (e.g., fatigue, muscle or joint pain, cold sensitivity, etc.), impairments (muscle weakness), and functional losses known as "post-polio syndrome" or PPS (Halstead & Grimby, 1995). But the health risks of aging with polio are not limited to changes in symptoms and/or declines in function. Living with the long-term effects of polio also places survivors at potentially increased risk for age-related chronic diseases and health conditions, such as diabetes, high blood pressure, heart disease, emphysema or COPD, osteoporosis, and obesity, to name just a few (Maynard et al., 1991). While these conditions affect the rest of the aging population, they may occur more frequently, and at younger ages, for persons with physical disabilities because of their "narrower" margin of health and the barriers they face in maintaining their health (DeJong, 1995; Marge, 1988; Pope & Tarlov, 1991).

The significance of both post-polio syndrome and early onset age-related chronic diseases lie in their potential to "accelerate" the aging process and produce "excess" or secondary disabilities (Lollar, 1994). Because of the costs of these consequences for individuals as well as society, preventing the new health risks of aging with polio, and other long-term disabilities, has become a major public health objective of the 21st century (Healthy People 2010: Draft for Public Comment, 1998; Brandt & Pope, 1998; Guralnik et al., 1996; Marge, 1988).

Recent findings from the Aging with Disability (AwD) Survey

Study\* illustrate the types of chronic health conditions persons with polio are at risk for as they age, and document the health disparities that exist between persons aging with polio and their non-disabled counterparts. To test for evidence of "accelerated aging," the frequency of selected chronic conditions reported by polio participants in the AwD Study was compared to national estimates of these same conditions for age-matched cohorts from the 1994-1995 National Health Interview Survey. The polio sub-sample of the larger AwD Study consisted of 218 individuals, who ranged in age from 42 to 89, and had been living with the effects of polio for an average of 50 years.

Out of the 14 chronic conditions examined in both studies, polio survivors reported significantly higher rates for almost all mortality and morbidity diagnoses compared to national estimates for age-matched cohorts. This pattern is most pronounced for the youngest group of 45- to 64-year-olds, where frequencies of chronic conditions are two to ten times greater for those aging with polio than for their same-age counterparts in the population at large. Key findings from this analysis are summarized below.

- "Low vision/blindness" was reported by 21.0% of younger polio survivors compared to estimates of only 4.5% for 45 to 64-year-olds in the population at large.
- 14% of polio survivors in each age group reported a diagnosis of emphysema/COPD compared to national estimates of only 1% and 4.6% for corresponding age groups.

- For mortality risk factors, 14.0% of polio survivors in the 45 to 64 age group reported a diagnosis of diabetes compared to only 6.3% for this same cohort in

the population at large. The disparity in rates of high blood pressure (HTN) is even greater. 41.0% of younger polio survivors report a diagnosis of HTN compared to 22.2% for this cohort in the population at large; and, among those 65 and older, the frequency of HTN is 54.0% among polio survivors compared to only 36.4% for the population at large.

Together, these findings document the health disparities of persons aging with polio and highlight their changing needs for health care. To reduce the risks of "accelerated aging," these findings suggest that persons aging with polio and their families need access to: more preventive services and at younger ages; more informed medical and allied health providers who are knowledgeable about the new health risks associated with aging with disability; and, more targeted health promotion programs that incorporate training in self-care and self-advocacy, as well as education on risk factors and the prevention of chronic disabling disease.

\*The AwD Study was conducted between 1993 and 1998, under the auspices of the Rehabilitation Research and Training Center on Aging with Disability, located at Rancho Los Amigos Medical Center, Downey, California. The full study involved a cross-sectional, group comparison study of persons aging with cerebral palsy, polio, rheumatoid arthritis, and stroke. The total achieved sample was 555.

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### **“Post-Polio Syndrome as a Model for Musculo-Tendinous Overuse Syndromes in Military and Civilian Populations”**

is the title of a research project that will be completed in June 1999. The project site was Philadelphia, PA (Pennsylvania), and the principal investigators were Drs. Mary Ann Keenan (Department of Orthopedics, Albert Einstein Medical Center), Alberto Esquenazi (Gait Analysis Laboratory, MossRehab Hospital), and John Whyte (Moss Rehabilitation Research Institute). Because overuse injuries are common among military recruits who are subjected to rigorous training regimens, the main goal of this project, which was funded by a grant from the Department of the Army, was to examine the relationship between weakness, overuse, and injury. The relationship is thought to be cyclical, with weakness causing overuse, overuse leading to increasing weakness, and both making a person vulnerable to injury, a pattern typical of many polio survivors as a result of everyday activities because of their muscle weakness. By studying overuse problems among polio survivors, the military gained knowledge about how muscle weakness is related to overuse and how the body compensates for it.

A total of 194 polio survivors participated in this project, their age ranging from 32 to 81 years. The average age at the onset of polio was 6.9 years; the average number of years since polio was 50.8, ranging from 29 to 80 years. When the subjects were asked to identify the sites where they had weakness or paralysis immediately following the original polio infection, the highest percentages were seen for the legs, with 57% for the left leg and 55% for the right.

Approximately 7% of the subjects stated that they were left with no noticeable weakness or paralysis.

One of the objectives of this project was to determine whether weakness in particular locations was likely to lead to symptoms of overuse in other areas, and the results indicated that leg weakness was strongly related to overuse symptoms in the arms, particularly the shoulders and wrists. Shoulder symptoms that could be identified by tenderness to the touch were more common among females. These symptoms were strongly related to knee extensor (quadriceps) strength and weight. Females whose combined knee extensor strength was less than 79 pounds were at much higher risk for having shoulder symptoms than those who were stronger. In addition, females who weighed more than 154 pounds were at much higher risk than those who weighed less. The most likely explanation is that weak knee muscles cause increased stress on the arms during tasks such as getting up from a chair or using an assistive device for ambulation. Increased weight also results in an increased demand on the arms during similar tasks.

Polio survivors who use assistive devices for ambulation (e.g., cane, crutches, walker, or wheelchair) were more likely to have symptoms of carpal tunnel syndrome (CTS) than those who do not. In particular, people who use wheelchairs tend to have significant weakness in their leg muscles: as the legs become weaker, the demand increases on the arms (e.g., during transfers), increasing the probability of symptoms related to overuse in the wrist, elbows, and shoulders.

Since many of the overuse symptoms in polio survivors occur in strong muscles used to compen-

sate for weak ones, the researchers needed to understand the strategies that people use to compensate for weak muscles. One study in this project looked at the effect of braces and shoe inserts on symptoms of plantar fasciitis (heel pain). Another looked at the different strategies used to get out of chairs of different heights when armrests were available and when they were not. The data analysis is still underway for these studies. However, preliminary results indicate that several different compensation patterns or strategies are involved.



Alexa Stuijbergen, PhD, RN, FAAN, Associate Professor, Division Chair, The University of Texas at Austin, School of Nursing, reports that she and her colleagues received continued funding from National Institutes of Health (NIH) for **their studies of health promotion and quality of life**. The five-year grant, for \$761,436 from NIH's National Institute of Nursing Research, will include both people with multiple sclerosis (MS) and people with post-polio syndrome. The intent is to examine how health behaviors (physical activity, nutrition, stress management, etc.) influence quality of life. For the last eight years, Stuijbergen has been studying aspects of health behaviors in people with MS and found that persons who work toward maintaining their own health through these self-care behaviors have a more positive quality of life. This study will examine how exercise, nutrition, stress management, and other behaviors are related to outcomes such as depression, employment, well-being, and quality of life. ■

## **The Global Situation of Polio Eradication**

The Region of the Americas is completing its seventh polio-free year, and in 1998, the Western Pacific region reported zero cases of polio. Of the cases reported to WHO in 1998, 2,527 (89%) originated in South East Asia, where India accounts for 2,181 of these cases. Improved surveillance in India (acute flaccid paralysis rate [AFP] 1.03) may help explain the number of cases being reported. In 1998, India conducted a National Immunization Day (NID) during which 130 million children under the age of five years were vaccinated.

In the European region, Turkey was the only country to report transmission of wild poliovirus, with 21 cases that occurred in the areas bordering Syria, Iraq, and Iran. A "cross-border" mop-up activity was conducted in that area during October-November 1998. The Eastern Mediterranean region reported 256 cases, 172 (67%) of which were reported in Pakistan. Afghanistan, which has improved AFP surveillance in 1998 despite an ongoing armed conflict, reported 31 cases of polio. The African region reported 39 cases to WHO in 1998. Efforts are being made in Africa to accelerate improvements in AFP surveillance, and additional resources are urgently needed.

Worldwide immunization coverage with three doses of oral polio vaccine (OPV) in 1998 reached 83% of infants, ranging from 62% in Africa to 94% in the Western Pacific. By September 1998, only four polio-endemic countries – the Democratic Republic of Congo, Liberia, Sierra Leone, and Somalia – had failed to carry out National Immunization Days (NIDs). However, whereas renewed civil war has caused NIDs to be postponed in DR Congo, the other three African countries had carried out their first NIDs by the end of 1998. ■

Excerpted from WHO/GPV Polio Eradication Web site (<http://whqsabin.who.int:8082>).

## **Recommended Childhood Immunization Schedule for Polio Vaccine for 1999: Inactivated Poliovirus Vaccine for First Two Doses**

As a result of progress in the global eradication of poliomyelitis, the need for further reductions in the risk for acquiring vaccine-associated paralytic polio, and the acceptance of inactivated poliovirus vaccine (IPV) by parents and physicians, the Advisory Committee on Immunization Practices (ACIP), the American Academy of Family Physicians (AAFP), and the

American Academy of Pediatrics (AAP) recommend IPV for the first two doses of poliovirus vaccine for routine childhood vaccination. The ACIP continues to recommend a sequential schedule of two doses of IPV administered at ages 2 and 4 months, followed by two doses of oral poliovirus vaccine (OPV) at ages 12-18 months and 4-6 years. The administration of IPV for all four poliovirus vaccine doses also is acceptable and is recommended for immunocompromised persons and their household contacts. OPV is no longer recommended

for the first two doses of the schedule and is acceptable only for special circumstances (e.g., vaccination of children whose parents do not accept the recommended sequential schedule, late initiation of vaccination that would require an unacceptable number of injections, and imminent travel to countries where polio is endemic.) OPV remains the vaccine of choice for mass vaccination campaigns to control outbreaks of wild poliovirus. ■

SOURCE: Center for Disease Control and Prevention's *Morbidity and Mortality Weekly Report*, 1999, 48, 12-16.

## **Impact of the Sequential IPV/OPV Schedule on Vaccination Coverage Levels – United States, 1997**

The Center for Disease Control and Prevention investigated the impact of the change to a sequential IPV-OPV vaccination schedule at two large West coast health maintenance organizations (HMOs) – Group Health Coopera-

tive (GHC) of Puget Sound, Seattle, and Kaiser Permanente of Northern California (KPNC), Oakland.

Among GHC children who received IPV as their first polio vaccination, vaccination up-to-date status by age 12 months for routinely recommended vaccines was 82%, 83%, and 82% in the first three quarters following implementation, and among those receiving OPV, vaccination up-to-

date status was 82%, 81%, and 79%, respectively. At KPNC, the quarterly up-to-date percentages were 90%, 89%, and 91% for children receiving IPV, and 92%, 90%, and 91% for children receiving OPV. ■

SOURCE: Center for Disease Control and Prevention's *Morbidity and Mortality Weekly Report*, 1998, 47, 1017-1019.

## Medicine and the Media

Medicine is both science and art. On one hand, it is a body of knowledge that is advanced through countless numbers of investigations, many of which make it into the headlines. On the other, it is also the work of hundreds of thousands of individual practitioners, a few of whom receive a great deal of media attention. Television, radio, books, newspapers, print periodicals, and the Internet contain a mix of medical information, both news and advice. It is often difficult to determine which items to ignore, which to file for future reference, and which to act upon.

### Medical News

The daily news is constantly abuzz with reports of scientific investigations. These may be generated by laboratory research, accounts of new procedures, reports from observational studies, and the results of clinical trials. While all may be scientifically valid, they vary widely in their applicability to personal health.

*LABORATORY EXPERIMENTS* – Studies in cell cultures and animals may provide hints of approaches that may or may not prove to be effective in humans. However, even the approaches that appear to be the most promising in the lab are usually years away from widespread application. Last year, great excitement over a potential cancer cure was generated by reports of experiments with angiogenesis inhibitor, a substance that prevents the development of new blood vessels needed to sustain tumor growth. However, at that time the substance had halted tumor growth only in mice, and,

many months later, it is still not available in quantities large enough for human studies.

*OBSERVATIONAL STUDIES* – These investigations, which fall into two basic classifications – prospective studies and retrospective studies – relate the lifestyles and physical characteristics of people to the diseases they develop. In prospective studies, such as the Nurses' Health Study and the Framingham Heart Study, researchers select a group of healthy people and track their lifestyle practices and the diseases they develop over several decades. In retrospective studies, which are considered less reliable, researchers identify people who have developed a disease, query them about their lifestyles in the past, and compare their habits to those of similar people who have not developed that disease. Because researchers who conduct observational studies can't control any aspect of the participants' lives, these investigations stop short of establishing cause-and-effect relationships.

*INTERVENTIONAL STUDIES* – These studies are designed to determine the effects of a particular intervention, be it a lifestyle change, drug, or medical procedure. The randomized, double-blind, controlled clinical trial is considered the gold standard of interventional studies. In this type of investigation, participants are randomly assigned to two or more groups, each of which receives either a placebo or a different intervention. Ideally, neither the participants nor the researchers know which group is receiving what treatment. In such cases, it's reasonable to assume that differences in results among the groups can be attributed to the intervention. One such study, the Postmenopausal Estrogen/Progestin(s) Intervention (PEPI) Trial, evaluated the effects of

three different hormone regimens and a placebo and determined the relative effects of each on serum lipid levels.

### Advice

Advice on health issues is more likely to be found in the features sections of periodicals, on television talk shows, infomercials, and public-television pledge-drive specials, and on the Internet. These health features may be based on recommendations from government agencies, such as the National Institutes of Health, or public interest organizations like the American Cancer Society. However, features on health topics are often based on less "official" sources – scientists, physicians, and other practitioners, and authors of popular books. In many cases, these individuals may be reviewing and interpreting information from research conducted by their groups or others in their field. In other cases, they may be promoting theories, philosophies, or programs that have not been validated by research or experience.

### Analyzing Information

Asking the following questions may help you to determine which information to act upon, which to ignore, and which to file in your memory bank.

*Was the information based on research?* Although personal anecdotes are often compelling, one individual's experience does not constitute a universal truth. For that reason, data generated by studies conducted in thousands of people are likely to be more meaningful than those derived by the experiences of a few.

*How many studies have produced similar findings?* Again, medical practice is established by

repetition: laboratory results that are reproduced over and over; observational studies that confirm the results of laboratory experiments or that reinforce those from other observational studies; and clinical trials that confirm laboratory experiments, observational studies, or other clinical trials. For example, although numerous observational studies have indicated that postmenopausal estrogen use reduces the risk of heart attack, clinical trials have yet to do the same.

*Who is dispensing the information?* If the information contains recommendations, it's good to know who is making them, particularly if those recommendations involve sweeping changes in health habits or medical treatments. Government agencies, research institutions, and public interest organizations periodically evaluate reams of data from studies and translate the information into guidelines for prevention, screening, and treatment. On the Internet, such reliable advice is more often found on Web sites ending in "gov" or "org" than on those ending in "com."

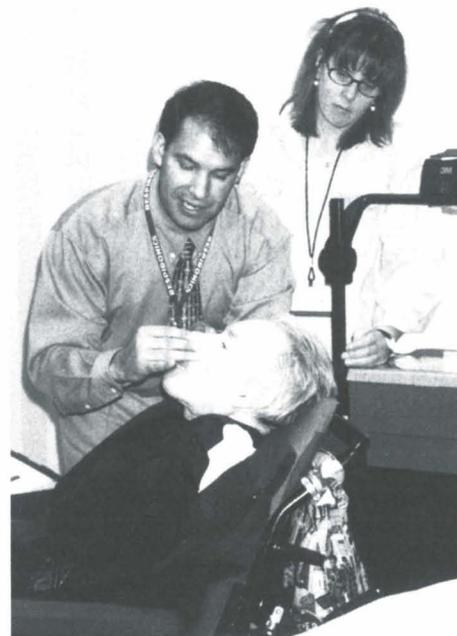
*What does your clinician think?* If you're considering making a major change in your habits on the basis of media information, get your clinician's advice. He or she can help you decide whether the change is appropriate for you. ■

Excerpted from the February 1999 issue of the *Harvard Women's Health Watch*, ©1999, Presidents and Fellows of Harvard College.

Individual and bulk subscriptions available. Contact the Harvard Health Publications Group, 164 Longwood Avenue, Boston, MA (Massachusetts) 02115 (617-432-1485).

Kimberly Pratt, RRT, Strong Memorial Hospital, Rochester, New York, participated in a session on custom mask-making at the *7th International Conference on Noninvasive Ventilation: Across the Spectrum from Critical Care to Home Care* held in Orlando, Florida in March. Joe Abeyta, Asia/Pacific Sales Manager for Respironics, molds silicone putty to the face of polio survivor Gary McPherson, Edmonton, Alberta, Canada. To complete the mask, straps and two 7.0 mm tubes are added. For more information, contact Respironics (800-638-8208).

Over 450 people attended the conference, sponsored by the American College of Chest Physicians (ACCP) and the American Association for Respiratory Care (AARC), in cooperation with International Ventilator Users Network (IVUN), National Jewish Medical and Research Center, and Journées Internationales de Ventilation à Domicile. *IVUN News* will feature additional information from the meeting. ■



(l-r) Mary Gould, BA, RN, project manager; David Gray, PhD, principal investigator; and Karen Hirsch, PhD, co-investigator for "Mobility, Disabilities, Participation and Environment."

Five hundred readers of *Polio Network News*, selected at random, recently received a letter of introduction and a packet of three questionnaires from researchers at Washington University in Saint Louis.

If you have returned the completed surveys, we thank you. If you have not, we encourage you to do so. The researchers do want your opinion about the questionnaires' content and how well the questions are written. *All responses are confidential.* The project is in the second year of a three-year grant funded by the Center for Disease Control and Prevention.

*Polio Network News* will update readers as information develops. ■

## Readers Write

"I am working with Dr. Paul Offit, chief of infectious diseases at Children's Hospital in Philadelphia and member of the CDC's Advisory Committee on Immunization Practices. Dr. Offit is writing a book about the Cutter polio vaccine incident. On April 12, 1955, Jonas Salk's inactivated polio vaccine was licensed. Twelve days later, a case of paralysis was reported, apparently stemming from the vaccine itself. Less than a week later, dozens of cases developed. Within days, it became clear that the children had received vaccine from one company – Cutter laboratories.

"We are asking that you help us identify recipients of the Cutter vaccine and/or their families."

Beth Waters, Cooney/Waters Group, Inc., 79 Fifth Avenue, New York, NY 10003  
(212-886-2200, 212-886-2288 fax, bwaters@cwg.com)

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"I have a friend who has been diagnosed with a ventral hernia causing separation of the muscles around his stomach. He has been told that surgery to correct the hernia is a consideration, but would involve a type of mesh around the muscles and the concern is how it might impact his gait or if his gait would cause the mesh to come apart or be negatively impacted. (The right side of his body was more affected by polio than the left; he wears an AFO and uses a cane to walk.) He is in constant pain from the hernia, but the value of the surgery certainly seems suspect. Have you heard of a similar problem? Is there any information on possible remedies?"

Jill, e-mail

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"Purchasing a mattress can be a very frustrating endeavor. I often tell people that they should find a friend or relative who owns the type of mattress they are thinking of getting, and then ask to take a nap on it. If you wake up feeling good, then

it may be a safe bet that particular type of mattress will work for you. There are no rules about which mattress works best for which type of problem. Some people do best with firm mattresses; others with soft ones or waterbeds. Some people with severe scoliosis may find soft mattresses more to their liking. It may be helpful to use special pillows or bolsters to help position yourself in bed comfortably. Do not forget to consider how easy it is for you to get in and out of the bed.

"If you have breathing problems, you might consider a bed with an elevating head. These beds have the added advantage of having separate controls for both sides of the bed. They are expensive but probably well worth the extra expense if you can afford it."

Marianne T. Weiss, MS, PT,  
University of Findlay, Ohio

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"I am a polio survivor and would like to communicate with someone in Spanish if possible because it would be easier for me. I live in the northwestern part of Mexico and in my country there is no information concerning PPS. I would appreciate any contact that you could provide for me or information in Spanish.

"Soy una sobreviviente de polio-mielitis y deseo comunicarme con alguien si fuese posible en español para más facilidad, yo vivo en el Noroeste de México y en mi país no hay información al respecto del síndrome postpolio (PPS). Les agradeceré cualquier contacto que puedan facilitarme o información en español."

Norma, Mexico

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"My name is Azzat Debsie. I would like to connect with other polio survivors who are 18 to 25 years old and who use assistive devices such as a calliper, brace, or ankle/foot orthosis."

Azzat Debsie,  
<edebsie@cyberia.net.lb>

"A nurse recently advised me to take cranberry pills (2 tablets, 4 times a day) rather than drink cranberry juice with its sugar content to assist me with my fight against urinary tract infections."

Larry, South Carolina

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"I have successfully won my appeal to my insurance company for coverage of exercises done in my small indoor swimming machine/pool. At the recommendation of my neurologist, my physical therapist teaches me exercises I can safely do. The insurance company has agreed to cover two sessions annually, as well as for assessments of my muscle status."

Susan, Vermont

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"In 'Use of Medication in People with Post-Polio Syndrome,' (*Polio Network News*, Winter 1999), Dr. Perlman states that in her experience centrally acting, non-narcotic drugs work best for 'true post-polio pain.' This has not been my experience. Nothing but rest usually does."

Frederick M. Maynard, MD,  
U.P. Rehab Medicine Associates, PC,  
Peninsula Medical Center,  
1414 Fair Avenue, Suite 119,  
Marquette, MI (Michigan) 49855  
(906-225-3914, 906-225-4583 fax)

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"The articles in the winter 1999 *Polio Network News* about two ventilator users who switched from Bantam ventilators to volume ventilation were very interesting. While it seems to be a difficult process for some former Bantam users, there can be many benefits including quieter ventilation, lower pressures required, lower power usage, and less ventilator upkeep.

"In Gary Presley's article, I noticed just a little detail that was incorrect. He said that the battery system in the PLV-100 is a NiCad system. The battery system is actually a sealed-lead acid system. Because it is a sealed system, these are safe on

airplanes and for other portable use. They do not require any routine battery maintenance, other than attention to recharging. The batteries are intended for power change-over between AC power and a large external battery, usually of the deep-cycle marine type.

"The issue of hypoventilation is a significant one for some post-polio survivors. Adequate nighttime ventilation is critical to continued overall health and function. There are many options in assisted ventilation today to aid in matching therapy to user."

Sarah Riley, MPA, RRT, former Product Manager, LIFECARE PLV Ventilators; currently Product Manager, Orthopedic Internal Fixation Devices, Synthes USA, Paoli, PA.

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"In 'The Switchover,' an article in the Winter 1999 issue of *Polio Network News*, Richard Wieler stated, 'Of course, the hunt to find a mask ...'

"I have been using a BiPap® S/T and also have been hunting for the perfect mask. After several attempts, I believe I have found the answer – a Sullivan Mirage™ mask, manufactured by ResMed Corporation, 10121 Carroll Canyon Road, San Diego, CA (California) 92131-1109 (800-424-0737, 619-689-2400, 619-689-2412 fax). The mask has a very unique feature regarding the forehead assembly. It is adjustable on both sides of the nose, thus eliminating air leakage."

Joyce, Ohio

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"I have been using a Bantam with a pneumobelt since 1961. Bantams are literally on their last breath. I tried a PLV-100 which has the necessary power for operating the pneumobelt. The breathing cycle is not comfortable because after the belt presses in on the abdomen, it deflates very quickly allowing the abdomen to drop abruptly. A PEEP valve was added and helped some. The most distressing prob-

lem was the loud noise made when the air came out of the valve each time the bladder deflated. The noise was terrible. Do you have any suggestions?"

Carole, Texas

*The reason the noise is more when using the PLV vs. the Bantam is because the exhalation valve on the PLV is on the outside of the device where with the Bantam it is on the inside. The PEEP valve probably helped some, but with a PEEP valve, expiratory pressure does not return to 0 or ambient pressure. To correct the "quick" deflation and to lessen the sound, an expiratory retard would be a better choice. This functions by creating resistance to exhalation and slowing the expiratory phase. Pressure does eventually return to 0 using this type of valve. Allowing the I/E ratio to be at 1:1 will help this to function as it should. It is also possible to muffle the sound of exhalation by placing an extra piece of tubing on the exhaust of the exhalation valve. This tubing can be insulated by wrapping gauze or material around.*

Susan Sortor Leger, RRT, Respirionics, Europe

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"I have swallowing problems and weakness on one side of my throat. Which way is it I am supposed to turn my head when swallowing?"

Ellen, Alabama

*Rotating your head to the weak side can improve your ability to swallow.*

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"I am enclosing a check as this year's contribution to The GINI Research Fund. How is it coming along?"

Doug, North Carolina



*The GINI Research Fund, thanks to a recent donation from the estate of Thomas Wallace Rogers, now totals \$115,000.*

*The fund, created by a Board resolution, allows for the income "to support the work of selected researchers seeking scientific information leading to eventual amelioration of the consequences of poliomyelitis and/or neuromuscular respiratory disorders."*

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"Is it possible to purchase or rent a copy of the PBS special, 'A Paralyzing Fear: The Story of Polio in America?' I did not see it when it aired."

Phyllis, Wisconsin

*The video "A Paralyzing Fear: The Story of Polio in America" (Item #A3317, \$19.98 plus \$4.25 shipping Parcel Post or \$6.25 UPS Ground; plus sales tax for CA, NY, VA) can be ordered from PBS Home Video, Catalog Center, P.O. Box 751089, Charlotte, NC (North Carolina) 28275-1089 (800-PLAYPBS, www.pbs.org/shop).*

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"The *Philadelphia Inquirer* provided extraordinary coverage about polio and its eradication February 21-25, 1999. For those who missed it, the Web site through which it can be accessed is <http://home.phillynews.com/packages/polio/text/indy21.asp>."

Sally, Quebec

*To order a reprint of the series, mail \$2 (USD) to the Philadelphia Inquirer, Back Issues, Box 8263, Philadelphia, PA (Pennsylvania) 19101. Be sure to include name and mailing address. Bulk orders are available by calling 215-854-4444.*

*A video, "A Day in the Death of a Disease," was also produced. The \$19.95 video can be ordered by sending your name, address, and phone number to Inquirer Service Counter Store, 400 North Broad Street, Philadelphia, PA (Pennsylvania) 19101. A representative from the Inquirer will contact you for your credit card number. ■*

EIGHTH INTERNATIONAL

# Post-Polio AND Independent Living Conference

SAINT LOUIS, MISSOURI

June 8-10, 2000

Saint Louis Marriott Pavilion

Downtown

Saint Louis, Missouri, USA

Proposals are requested which:

- ◆ Address the health care needs of people with disabilities, specifically the survivors of polio and the users of mechanical ventilation;
- ◆ Encourage interaction between people with disabilities and health care professionals;
- ◆ Examine and/or promote the independent living philosophy;
- ◆ Propose solutions to the major issues facing people with disabilities.

Presentations can be made either by one individual (20 minutes), by an individual with small group participation/discussion (1<sup>1</sup>/<sub>4</sub> hours), or by a group of individuals (1<sup>1</sup>/<sub>4</sub> hours) as a workshop or panel discussion.

Proposals must include name, complete contact information, and resume of presenter(s) (if group presentation, designate lead presenter), title of presentation, length and form of presentation, purpose and goals of presentation, and description (750 words) of presentation. Mail two copies by **July 1, 1999** to GINI, 4207 Lindell Boulevard, #110, Saint Louis, MO (Missouri) 63108-2915.

Participants whose proposal(s) has/have been accepted will be notified by October 1, 1999. The registration fee will be waived for the day(s) of the presentation(s).

## Calendar 1999

*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.*

**Third Annual Post-Polio Educational Symposium -- Past, Present, Future: Post-Polio in the New Millennium.** MAY 22, Harbor Pines Golf Club, Egg Harbor Township, New Jersey. Speakers include Kathryn Black, writer; Ed Snapp, PT; Futures Unlimited; and Jack Martin, PT, Coordinator of the Post-Polio Program, Bacharach Institute for Rehabilitation. Contact Linda Feinstein, Atlantic County Post-Polio Support Group (609-407-9180, LynFein@aol.com).

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

**Post-Polio Conference,** SEPTEMBER 17, Embassy Suites Hotel, 555 South 10th Street, Omaha, Nebraska. 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, mjbarnett@worldnet.att.net).

**First Annual Indiana Polio Survivors Association (IPSA) Post-Polio Conference,** SEPTEMBER 18, Methodist Hospital of Indiana, Indianapolis. Contact Rebecca Balsley, IPSA, P.O. Box 441226, Indianapolis, IN (Indiana) 46244 (765-759-9094, ipsa1@juno.com).

**Post-Polio Seminar,** NOVEMBER 13, Marietta Conference Center, Marietta, Georgia. Speakers include Richard Bruno, PhD, and Nancy Frick, MDiv, LhD. Contact Atlanta Post-Polio Association, P.O. Box 250566, Atlanta, GA (Georgia) 30325 (404-350-7631, bgbonham@mindspring.com).

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