

POLIO NETWORK NEWS

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International Polio Network

Osteoporosis

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Osteoporosis refers to a decreased density (mass per unit volume) of normally mineralized bone which is below that needed to maintain the skeletal function of adequate mechanical support. Fractures are the most important complication of osteoporosis, with associate pain, deformities, and loss of function.

More than 1.5 million Americans have fractures attributable to osteoporosis each year. A reduction in osteoporosis-related fractures can be achieved by a reduction in falls, and by prevention and treatment of bone loss. This essay will be primarily concerned with methods of preventing and treating bone loss as a result of osteoporosis.

Survivors of paralytic poliomyelitis may have a greater risk for osteoporosis-related fractures. Weakness from poliomyelitis may have caused a chronic reduction in or complete absence of weight bearing activity, with a resultant reduction in bone mass. (This residual weakness from past paralytic polio may also predispose post-polio individuals to more frequent falls.) In addition, a long period of immobilization at the time of acute poliomyelitis or after a surgical procedure could have produced significant bone demineralization. Studies show that as much as 30-40% of bone mass may be lost after six months of complete immobilization. However, restoration of normal activity may result in reversal of disuse-related bone loss.

For these reasons, maneuvers to prevent a further loss of bone mass and to decrease the risk of falls may be necessary to prevent osteoporosis-related fractures in post-polio individuals. Unfortunately few studies have assessed the effect of specific therapies on osteoporosis resulting from disuse and various disease processes.

Living bone is never metabolically at rest; it is continually undergoing a process of remodeling through new bone formation and bone resorption (to "dissolve"). This is accomplished through the action of

specialized bone cells called osteoblasts and osteoclasts. Osteoblasts are bone cells which produce new bone, whereas osteoclasts are bone cells which resorb or destroy bone. Usually there is a balance between the process of bone resorption and formation. Osteoporosis can occur either with a relative increase in bone resorption or a decrease in bone formation.

The structure of bone is not uniform throughout the skeleton. There are two types of bone: trabecular and cortical. Trabecular bone is concentrated in the spine at the end of long bones (such as at the hip). Because

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Vaccine Injury Compensation: A Battle Won

Shannon Dickson contracted polio in late 1962, when he was 10, after receiving the oral polio vaccine on a Sabin Sunday. Within two weeks he developed the classic fever, rigid back, and neck pain. He remembers falling down going to the bathroom, having weakness in all four limbs, and swallowing problems.

He wore leg braces for approximately nine months, went through a year and a half of intensive physical therapy for his legs and shoulders, making a complete recovery with some atrophy of the pectorals.

Because his was the only recorded case of polio in the Houston area at the time, he and his family commonly accepted that it was vaccine caused. Throughout the rest of his childhood, Shannon forgot about polio and participated in sports and many outdoor activities.

During the late '70s and '80s fitness boom, he started jogging and light weight lifting. Within a year he experienced multiple sprains and strains, muscle fatigue, and secondary orthopedic problems.

In 1984, he began tripping and falling. Also at this time, he was in a minor auto accident which ended up being a smoke screen. For the next three years, his problems were blamed on the accident. In 1987, he had a cervical fusion for a ruptured disc. He had

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**REMINDER!! As of September, 1991, our address, telephone and fax numbers are:
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osteoporosis involves primarily a loss of trabecular bone, areas with predominantly trabecular bone are at greatest risk for osteoporosis-related fractures.

The two most common types of osteoporosis are postmenopausal osteoporosis and age-related osteoporosis. Both occur as part of the normal aging process. Bone mass normally increases until the age of 30. After a short period of stabilization, age-related bone loss begins. In women, the rate of bone loss increases to 2-3% a year following menopause. However after 8-10 years, this rate of bone loss returns to baseline levels. Over their lifetimes, women lose about 50% of the trabecular bone and 30% of the cortical bone, and men lose about 30% and 20%, respectively. Thus, the degree of peak bone mass attained in early adulthood together with the rate of subsequent bone loss will influence the probability of developing osteoporosis later on in life.

Postmenopausal osteoporosis involves primarily an increased bone resorption, while age-related osteoporosis involves primarily decreased bone formation. Other less common causes of osteoporosis need to be considered in a patient with bone loss. These rarer forms can include hereditary causes of osteoporosis, endocrinological abnormalities, diet-related osteoporosis, drug-induced osteoporosis (from drugs such as glucocorticoids, methotrexate, and some anticonvulsants), disuse osteoporosis (e.g. from immobilization due to illness or neurological causes), disease-related osteoporosis, and idiopathic osteoporosis (of unknown cause).

Many factors which can influence the attainment and

DR. DARIA TROJAN is a physiatrist currently working at the Montreal Neurological Institute and Hospital, and at the Jewish Rehabilitation Hospital, Quebec, Canada. After completing her clinical training in Physical Medicine and Rehabilitation, she spent three years as a clinical and research fellow at the Montreal Neurological Institute and Hospital. Her research work focuses on post-polio syndrome (PPS). As a fellow, she studied neuromuscular junction transmission defects in PPS, and their response to anticholinesterase agents. Current research activities are concerned with identifying risk factors for PPS, developing a diagnostic test for PPS, and developing measures of function for patients with PPS. In the future, she also hopes to develop a specific treatment for PPS using recently identified neurotrophic factors. Dr. Daria Trojan works with a group of physicians, researchers, and health professionals based at the Montreal Neurological Institute and Hospital, and other departments at McGill University. Her co-workers include Neil R. Cashman, MD, Daniel Gendron, MD, Monica Kilfoil, MSc, Lois Finch, MSc, Ruth Dannenbaum, MSc, Diane Ste Pierre, PhD, Stanley Shapiro, PhD, and John Esdaile, MD, MPH.

maintenance of peak bone mass have been identified. Race is important in the development of osteoporosis. Blacks have a greater bone mass than whites and Orientals at all ages, and thus a lower prevalence of osteoporosis. Osteoporosis occurs less frequently in persons from southern Europe than in those of northern European descent.

Nutritional factors, primarily inadequate calcium and vitamin D intake, are implicated in the development of osteoporosis. Our need for calcium increases as we grow older because of less efficient intestinal calcium absorption, and other causes. The recommended calcium intake for young adults is between 750-1000 mg per day. Healthy premenopausal women over age 30 need about 1000 mg calcium per day (that amount contained in one quart of milk) and pregnant and lactating women need 1500 and 2000 mg per day, respectively. Individuals over age 50 need 1500 mg calcium per day. Unfortunately, the average American woman consumes less than 500 mg calcium per day and thus is in a chronic state of calcium deficiency.

Vitamin D is needed for intestinal absorption of calcium. The active form of vitamin D is produced in our skin by a reaction stimulated by ultraviolet radiation (in sunlight). Certain behavioral factors important in the development of osteoporosis have also been identified. Daily weight-bearing activity is essential for skeletal health. Studies have shown a direct relationship between weight-bearing activity and bone mass. In addition, behaviors such as cigarette smoking and excessive alcohol intake can induce bone loss.

Prevention of osteoporosis is currently the only reasonable management approach for this condition. An adequate calcium intake should be maintained in postmenopausal women. Calcium supplementation at doses of 1000 mg per day or more may decrease postmenopausal bone loss by as much as 50% at some sites. The result in premenopausal women from such supplementation are unclear. However, calcium supplementation has not been shown to replace the effects of estrogen-replacement therapy in postmenopausal women. Vitamin D supplementation may also be needed. Weight-bearing exercise such as walking or aerobics (if possible) should be encouraged. There appears to be a relationship between degree of weight-bearing exercise and bone mass. In addition, a regular weight bearing exercise program has been shown to increase bone mass in post-menopausal women. Cigarette smoking and excessive alcohol intake should be avoided because these behaviors can be damaging to bone. If possible, drugs that can cause bone loss should be avoided.

In those patients who have a low or relatively low bone mass, medications may be necessary to reduce post-menopausal and age-related bone loss. Currently the most effective treatment for this is estrogen-replacement therapy started at menopause. Estrogen therapy is most effective when started early after menopause. Estrogen therapy can prevent early post-

menopausal bone loss, can increase bone mass in the spine by 5% in women with osteoporosis, and can reduce fractures by 50%.

Estrogen use, however, has certain associated risks such as an increased incidence of endometrial cancer and possible an increased incidence of breast cancer. Estrogen therapy is also contra-indicated in certain patients. In women who are unable to take estrogens or in men, calcitonin can be used. Currently, calcitonin is administered intravenously. A form of calcitonin which can be administered with a nasal spray is available in Europe and is undergoing evaluation for use in North America. Calcitonin has been shown to transiently increase trabecular bone mass and to retard bone loss from cortical bone in post-menopausal women. Fluoride increases bone mass, however the bone formed was found to be abnormal and more susceptible to fracture. It is possible that a lower dosage of fluoride may still be helpful. Other possible treatments that are currently undergoing evaluation are biphosphonates, parathyroid hormone, and growth factors.

The prevention of osteoporosis-related fractures should also include strategies to reduce the risk for falls. Prevention of falls can involve various measures such as discontinuation of sedating medications, use of a leg brace, use of a cane or crutch to improve balance, use of rubber-heeled shoes, absence of "throw-rugs," and use of a night light.

In conclusion, even though much work remains to be accomplished on the prevention and management

New Polio Clinics Open

Department of Rehabilitation Medicine at New York University Medical Center, 400 E 34th St., New York, NY 10016 has recently opened a post-polio clinic. The clinic will be directed by Dong Ma, M.D. Call 212/263-6339 for appointment information.

The Physical Medicine and Rehabilitation Center, PA in New Jersey, 15 Engle St., Suite 205, Englewood, NJ 07631 USA (201/567-2277, FAX 201/567-7506) also has recently opened a clinic under the auspices of Donald Liss, MD, and Howard Liss, MD.

Participants Needed

Post-polio survivors are needed as volunteers for a research project at the University of Texas Southwestern Medical Center at Dallas. The purpose of this study is to examine changes in the ankle, hip, and knee motion that occur during walking in persons, with a history of polio.

All testing is non-invasive and can be completed in one afternoon. The study is a non-compensated study. It requires that the subjects be ambulatory and without cardiopulmonary disease.

If you are interested, please call Melody Sykes at the Mobility Research Lab at 214/351-2041.

of osteoporosis, some recommendations and specific treatments are available. New medications may become available in the next decade that are more easily administered and are more effective in treating established osteoporosis.

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This article first appeared in *Folio Polio*, the newsletter for Polio Quebec.

Resources:

National Osteoporosis Foundation, 1150 17th St., NW, Suite 500, Washington DC 20036 USA (202/223-2226) offers educational materials.

Osteoporosis: The Bone Thinner, Menopause, Managing Menopause, and Should You Take Estrogen? are available from **National Institute on Aging**, P.O. Box 8057, Gaithersburg, MD 20898-8057 USA (800/222-2225). They will also send a complete listing of their publications upon request.

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Vaccine Injury Compensation: A Battle Won Continued from page 1

surgery again in 1988 for another. His symptoms worsened and when a third fusion was recommended, he refused.

Shannon consulted with a friend who was an orthopedic surgeon at the University of Texas Southwestern Medical School in Dallas. Through his friend, he was referred to a neurologist at the University, and the extent of his polio was uncovered by electromyography (EMG). They conducted more tests, and he was finally diagnosed with post-polio muscular atrophy (PPMA — progressive new weakness and/or atrophy in muscles with clinical or subclinical signs of chronic partial denervation/reinnervation compatible with previous acute polio).

He was then sent to Dallas Rehabilitation Institute (DRI) where he became connected with the post-polio community. There he was fully educated about post-polio problems and the need for lifestyle changes. Shannon's condition continued to progress with loss of muscle strength and size, swallowing problems, and pain. After visits to Jacquelin Perry, MD, at Rancho Los Amigos in Downey, CA, he began wearing a modified Florida brace for his neck. He subsequently retired from work.

It was six months after his diagnosis that he heard about the National Vaccine Injury Compensation Program. Meeting the deadline required a lot of work, but Shannon's case was clear — it was the oral (live) vaccine, it was an isolated case (no ongoing epidemic), and he had affidavits from several collaborating witnesses. Shannon's settlement was the first case with the late effects of polio, rather than the initial bout, as the main concern.

Since the settlement, Shannon has testified at a public hearing by the Institute of Medicine on vaccine safety. He testified to his history, making the point that the initial effects of polio may not be the full story.

A BATTLE TO BE WON

Other polio survivors have filed claims stating that their polio was caused by the Salk vaccine, which is defined as inactivated, even though safety standards at the time allowed for five live virus within every 100,000 vaccinations produced. For compensation in these cases, the government requires scientific proof that the vaccine contained the live virus complete with manufacturer and lot number, and proof that the polio was not contracted from a wild virus — which is very difficult, if not impossible, to do especially during epidemics.

John R. Brydon, Esq., Long Beach, CA, has filed a brief attempting to establish the Salk vaccine as other than inactivated polio vaccine and entitled to a presumption of causation. The purpose of this test trial is to present scientific evidence to justify shifting the

burden of proof away from the petitioners and creating a presumption that polio contracted within 30 days after receipt of an inactivated polio vaccine (IPV) injection was caused by the vaccine.

The polio survivors, on whose behalf the brief was filed, believe that the mass polio immunization programs of the '50s saved many lives and helped eradicate the devastating effects of polio in the U.S. Likewise, they expect the government's current immunization programs to further reduce the negative impact of other contagious diseases.

Their wish is that throughout these efforts the government will be responsible: first, in educating physicians and consumers about the various vaccines and their suitability given children's health conditions; secondly, in allocating adequate funding for both post and pre-Act claims; and finally, by reasonably redefining the criteria for IPV recipients which would allow those adversely impacted, by a government-mandated program, to obtain medical assistance to deal with the effects of their polio.

A hearing will probably be held in Washington, DC, this fall.

An Untold Vaccine Story

Herbert Ratner, MD, was health officer of Oak Park, Illinois, from 1949 to 1974. During his career, he became very knowledgeable about the Salk vaccine, the National Foundation, and the United States Public Health Service's (USPHS) Salk vaccine program. He has written about what happened during this tumultuous period from the introduction of the Salk vaccine in the 1954 field trial until its replacement by the Sabin vaccine.

An Untold Vaccine Story is being printed in *Child and Family*, a publication of the National Commission on Human Life, a non-profit organization to which Dr. Ratner donates his full-time services. Readers interested in obtaining the material (70 pages distributed through eight issues of *Child and Family*) may do so by donating \$25 or more to the Commission. Contact Herbert Ratner, MD, Box 508, Oak Park, IL 60303, USA.

Oral Polio Vaccine (OPV)

OPV should not be used to immunize immunocompromised patients, their household contacts, or nursing personnel in close contact with such patients; eIPV is recommended for such persons. Immunocompromised patients may be unable to limit replication of vaccine virus effectively, and administration of OPV to children with congenital immunodeficiency has resulted in severe, progressive neurologic involvement. Although a protective immune response to eIPV in the immunocompromised patient cannot be

assured, the vaccine is safe and may confer some protection. If OPV is inadvertently administered to a household or intimate contact (regardless of prior immunization status) of an immunocompromised patient, close contact between the patient and the recipient of OPV should be avoided for approximately one month after vaccination, the period of maximum excretion of vaccine virus. Because of the possibility of immunodeficiency in other children born to a family in which there has been one such case, OPV should not be administered to a member of the household in which there is a history of inherited immunodeficiency until the immune status of the recipient and other

children in the family is documented. Although OPV has not been harmful when administered to asymptomatic HIV-infected children, iPV is the vaccine of choice for a child who is known to be infected. Evaluation and testing for HIV infection of asymptomatic children are not necessary before decisions concerning immunization with live-virus vaccines are made.

Source: Recommendations of the Advisory Committee on Immunization Practices (ACIP): Use of Vaccines and Immune Globulins in Persons with Altered Immunocompetence, Morbidity and Mortality Weekly Report, April 9, 1993/ Vol. 42/No. RR-4.

UPDATE ... UPDATE ... UPDATE ... UPDATE ... UPDATE

ON POLIO OUTBREAK

During September 1992—February 1993, 68 cases of poliomyelitis occurred among members of a religious community in the Netherlands. Because members of an affiliated religious community in Alberta, Canada, had direct contact (i.e., travel to and from the Netherlands) with members of the affected community, health authorities in Alberta conducted an investigation during January-February 1993 to determine whether this poliovirus had been imported.

The investigation focused on a small rural community in southern Alberta, comprised of members of a religious group that generally opposes vaccination.

Wild poliovirus type 3 (PV3) was isolated from stool specimens obtained from 21 (47%) of 45 persons (primarily children). Laboratory investigations determined that this PV3 was virtually identical with the strain that caused the recent outbreak in the Netherlands.

No cases of paralytic poliomyelitis have been identified in Canada since 1988. Provincial epidemiologists in Canada, in collaboration with the Laboratory Center for Disease Control in Ottawa, have enhanced surveillance for cases of acute flaccid paralysis. In addition, poliovirus vaccine has been offered to members of all unvaccinated communities.

Centers for Disease Control Editorial Note: The findings in this report represent the first documented importation and circulation of any wild poliovirus in the Western Hemisphere since the apparent eradication of wild poliovirus infection in August 1991. No cases of paralytic poliomyelitis have been reported from the affected community in Alberta.

The risk for exposure, infection, and paralytic disease among vaccinated persons in the general population is low. Therefore, persons fully vaccinated with poliovirus vaccine are not considered at increased risk for poliomyelitis, and special efforts (i.e., additional vaccination) are not recommended.

Because of the risk for importation and spread of poliovirus, all persons age <18 years who are not fully vaccinated should initiate or complete the primary series of poliovirus vaccine according to the recommendations of the Advisory Committee on Immunization Practices. In addition, special efforts are necessary to increase acceptance rates of vaccination and to provide poliovirus vaccines to unvaccinated or incompletely vaccinated members of religious groups who do not generally accept vaccination.

The documentation of imported wild poliovirus in Alberta — following a period of 18 months during which wild poliovirus was absent in the Americas — demonstrates the potential for reintroduction of poliovirus into areas where poliomyelitis was considered eliminated.

Source: Excerpted from Canada Communicable Disease Report, 1993; 19:57-8, and from *Morbidity and Mortality Weekly Report*, 1993; 42:337-9.

ON SCOLIOSIS

Polio Network News heard from Philip J. Mayer, MD, Associate Professor Clinical Orthopaedics, Wayne State University, Detroit, Michigan. He writes, "I read about your organization in the *Spinal Connection*, and I do agree that it is important to build awareness about polio-related scoliosis. In the '70s, I had the unique experience of living in a house on the grounds of the Victory School, a school for polio children in Taiwan. At the time, we estimated there were 55,000 post-polio individuals. I had the honor of working with a small group of physicians in a project known as the Pink Tung Scoliosis Foundation. Virtually our entire practice was dedicated to the treatment of children and adults with post-polio spinal deformities. The environment was extremely modest and, as a surgeon, I functioned quite on my own. In 1979, I reported to the Scoliosis Research Society, the results with our first 118 consecutive post-polio scoliosis patients, and this series was subsequently run to approximately 350 patients and published in *Spine*. I now limit my practice to spine surgery."

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ON L-CARNITINE

What's Happening With Research Medications, Polio Network News (Vol. 8, No. 4), discussed information received from a polio survivor/physician in Switzerland regarding L-Carnitine and Acetyl-L-Carnitine.

The physician, Dr. med Thomas Lehmann, wrote to explain that his patients are taking L-carnitine, not Acetyl-L-carnitine, and are reporting "increased strength, endurance, and less fatigue, enabling them to manage their daily work and free time with less difficulty."

The amino acid L-carnitine is essential for metabolic processes and plays an important role in the lipid-related energy production of the skeletal muscles. It is synthesized in the human body from the amino acids lysine and methionine. In sports medicine, it is being administered to compensate for the loss of body L-carnitine under extreme or long-duration physical exercise (i.e. marathon running).

Some natural L-carnitine food sources mentioned in descending order of mgs/100 gms are: sheep meat (210), lamb meat (90), beef (60), pork (30), chicken (7.5), yeast (2.4), milk (cow), (2.0), and avocado (1.3).

L-carnitine is available as a nutritional supplement in the U.S.

References: Influence of L-carnitine administration on maximal physical exercise, L. Vecchiet et al, *Eur. J. Appl. Physiol.* (1990) 61:486-490; Carnitine and Acylcarnitine Metabolism during Exercise in Humans: Dependence on Skeletal Muscle Metabolic State, William R. Hiatt et al, *J. Clin. Invest.* (1989) 84:1167-1173.

FROM NATIONAL CENTER FOR HEALTH STATISTICS

The 1994 National Health Interview Survey (NHIS) will include extensive disability questions, including questions regarding polio. Polio survivors identified in this nationally representative household survey will be asked specific questions about the history of their illness. The new survey will permit validation of the number of polio survivors estimated from the 1987 NHIS. The 1987 NHIS estimate of about 640,000 paralytic polio survivors was substantially higher than any previous record-based estimates. The 1994 survey will also provide the first population-based national estimate of the number of polio survivors experiencing the late effects of polio. Data from the survey will be available in 1995.

FROM COALITION

The National Post-Polio Research Coalition was formed last year when the Polio Society asked the International Polio Network to help reach support groups nationwide. at the goal was to encourage active

participation in the political process by educating congressional representatives about the needs of polio survivors and the need for research into effective cause(s) and treatment(s) of post-polio syndrome.

Lauro Halstead, MD, testified before the House and Senate Committees on Appropriations in 1990-2. Disease-specific groups were not invited to testify this year.

In 1991, the Polio Society was successful in encouraging the National Institute of Neurological Disorders and Stroke (NINDS) to enact a program announcement for research in post-polio syndrome. However, since program announcements do not require the allocation of funds specifically for polio research, the Research Coalition was formed in 1992 to rally survivors and health professionals alike, nationwide, to educate representatives about the need for a specific request for proposals (RFP) which does allocate specific funds. Unfortunately, a specific RFP was not issued in 1992, although the program announcement is still in effect.

Activities in 1993 and in the future will be directed toward ensuring that a constant stream of reminders about the presence of polio survivors, our numbers, our strength and our persistence, and will be directed toward congressional representatives.

It remains important for all of us to be in touch with our Senators and Congresspersons about post-polio issues. Participation in the Coalition's annual postcard blitz, a short letter, or phone call can make a difference. The Appropriations Committees will decide on budget recommendations in late September.

Report & Video Available

◆ In the Spring of 1993, Sunny Roller, polio survivor and coordinator, Diversity Program, University of Michigan Medical Center, and Eva Wortz, visited Germany to investigate health spa practices and study their possible application to individuals with chronic disabilities. The final report, **German Health Spa Practices and Their Applications in Preventing Secondary Disabilities: Report of a Polio Study-Visit to Three Spas in Bavaria**, is available from World Institute on Disability, 510 16th St., Oakland, CA 94612 USA (510/763-4100) or Rehabilitation International, 25 E 21st St., New York, NY 10010 USA (212/420-1500).

◆ "What Do We Do Next? A Lesson from Germany" can be borrowed from International Polio Network. The 20-minute video takes its viewers on a tour of a German health spa, and features an interview of Renate Schindler, a polio survivor who has taken advantage of the health spa system. Support groups interested in borrowing the tape, and the suggested discussion questions, for an upcoming meeting should contact International Polio Network, 5100 Oakland Ave., #206, St. Louis, MO 63110-1406 USA (314/534-0475).

Readers Write



DEAR JOAN:

"Being a survivor of polio is a bit like being a dinosaur whose bones are constantly being discovered and whose extinction is open to various theories. Most recently, there has been interest and research into the effects of polio on those people who survived the last epidemics before the vaccine. I contracted polio at the age of two in 1949 and have no recollection of myself without the residual paralysis of my right leg which required, and still requires, the use of a long leg brace.

"Most recently I felt myself tiring easily and experiencing difficulty in performing tasks which previously were more accessible. At first glance, I blamed myself and the aging process for this inability to maintain my former level of activity. After some research, I found a doctor who correctly diagnosed my condition as post-polio syndrome, a diagnosis which greatly benefited my physical and psychological state. I then began to reach out for literature and support groups.

"Along with much valuable information, I was distressed to find that a mind-set seems to permeate the literature, a mind-set that depicts polio survivors as victims and characterizes past successes as over-achieving or the result of an excessive need to be 'normal.'

"A popular trend in our culture makes victims of people in order to more easily focus on the source of the problems they face. For example, overeaters, alcoholics, and drug abusers are encouraged to trace their problems back to various forms of abuse they may have suffered in the past. Memories surface so the patient can re-experience the victimization and overcome the problem. I certainly do not question the existence of child abuse, or the trauma of growing up in a family with an alcoholic parent; what distresses me is the propensity to victimize many types of behavior in the interest of pursuing quick fixes. We must recognize that formulas and easy explanations may provide only a part of the answer. Indeed, psychologists are coming forward to state that while memory is an imperfect instrument, it gives clues to a person's interior life.

"In the case of recent post-polio literature, there appears to be a tendency to paint polio survivors as victims of the medical system which used barbaric means to help cure them, victims of families repulsed by their disabilities, and victims of a society which only wanted them to go away and be normal. Indeed, there is an inference that the achievements and successes of polio survivors only demonstrate their need to deny their handicap. 'Being in denial' appears to be the preferred way of viewing the past, which for many includes a full life of family, children, education, and career.

"I do not remember undergoing any physical abuse at the hands of medical personnel. Nor do I remember anyone being repulsed by my disability. I would sooner say that people felt sorry that this terrible thing happened and tried to give me every advantage. I do remember being stared at, which hurt a great deal. My family and friends were quick to explain that these people were impolite and uninformed.

"Recent literature recalls that children with polio were expected to be good and polite children who did not speak up. Weren't all children held to that same standard? I am not saying that hospitalizations at the ages of two, seven, and ten were not terrorizing and lonely. Any child or adult who is hospitalized and cut off from their loved ones experiences similar feelings, whether the illness is polio or heart disease. Should our health professionals have been more aware of the psychological difficulties facing the polio patient? Of course! But how sophisticated were they in dealing with other illnesses in the 1940s and 1950s? Should our families have been more sensitive? Of course! But family life is extremely complex, under the best circumstances. Should society have been more aware of the needs of the handicapped? Of course!

"The question remains: how useful is it to think of ourselves as victims? Life is complex, both for individuals with a disability and those without. We would not misuse a body of research and expertise so important to post-polio survivors by insisting on a standard of 'political correctness.' Redefining successful struggles to deal with very physical handicaps as 'denial' belittles the patient's personal history. Instead, say that we did what we could given the knowledge and resources available to us. Now we face a new challenge. Our common experience is a resource which can help us move forward. Viewing ourselves as victims compromises that effort." **Joyce, New York**

Dear Joyce: Thank you for your thoughts, and thank you for putting them on paper. I believe there are many survivors who will agree with you. We hurt our efforts to find solutions to our problems by trying to make us all alike.



"I was quite impressed with your presentation Saturday, at the Long Beach Conference. I was particularly happy with your reiteration of what others had said, that we must make use of all the anecdotal information, that our (the survivors) thoughts and feelings are valid, that there are lessons to be learned by documenting successful treatments. I was then saddened to hear that you are only an 'information shuffler' and that you only file our letters. Here's my 'Cure of the Month.' It is not based on vitamins (though I take them), or diet (though I am careful), or magic. It is based on the theory that a lot of the weakness and

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joint instability of post-polio is due to the overuse and thus loss of elasticity of the ligaments and tendons.

"I got polio in 1955 at the age of 11. I was not paralyzed, and a few years of physical therapy and exercise cured my limp and I regained my strength.

"I was diagnosed with post-polio syndrome in 1985, after suffering increasing pain, weakness, and fatigue for two years. Needless to say, I did not like what the physician had to say. I did not want to change my lifestyle, cease my acupuncture, or stop exercising. (I was jogging three miles a day.) I did not want to put my back and neck brace back on. So I did the opposite of what was prescribed.

"I went to a sports medicine orthopedist. On examination, finding me hyper-mobile, he felt the problem was due to overuse of the ligaments and subsequent disuse of the fibers in the belly of the muscles.

◆ He gave me dextrose shots in the lumbar joints to cause scarification, thus tightening the ligaments.

◆ He sent me to a Rolfer (deep tissue massage) who slowly (and painfully) separated the muscles fibers, getting rid of the stiff gel and allowing the fibers to be separate. (This therapy was exactly the same I had had when recovering from polio, by a doctor who had worked with Sister Kenny in Australia.)

◆ I went to a physical therapist who gave me tiny little isometric strengthening exercises, with no stretching, because I would be stretching the ligaments.

◆ He told me to walk a little every other day.

"That was six years ago. The incredible pain and exhaustion I had which caused me to see the physician is gone. Yes, I still have weakness and pain. Yes, I must see my physical therapist for joint mobilization at least once a month. But...I am better.

"Isn't it possible that some of the weakness is due to the stretching of the ligaments and tendons, over the years? Why can't somebody, somewhere, investigate that?

"If the survivors' input is indeed important; if it is important to share 'things that have worked,' if we need PAR (participatory action research), here is my participation hoping to have some research on this matter.

"I must be candid, through the years I have written to many post-polio physicians, NIH, support groups, etc., but have received no response. Even physicians attending this conference were not interested. When it was stated over and over again at the conference that our opinions need to be respected by the medical profession, I thought, YES, we need to be respected by our OWN physicians as well." **Planaria, California**

Dear Planaria: Don't underestimate the benefit, and even power, of information. I, perhaps, did not make it clear that the information does not stay in the file. It is added to, checked out, and scrutinized. I have learned

that misinformation is equally as powerful, but not to our collective benefit.

"Dear Planaria: Thank you for sharing your letter to Ms. Headley and your experience with management of the late effects of polio. Your story effectively describes the symptomatic (pain) and functional (difficulty walking) results of a chronic back problem due to hypermobility of the supporting ligaments that must maintain bones and joints in normal relationship to each other. Scarification is an infrequently used treatment in most medical rehabilitation circles, but is probably deserving of further investigation and definitely is a sensible treatment to consider if ligament hypermobility is assessed to be a problem by a qualified medical practitioner. You and your physician are to be acknowledged for having arrived at an effective treatment plan that addressed several problems simultaneously (hypermobility of ligaments, local myofascial pain and swelling, disuse weakness and deconditioning). Your story clearly reflects a strong commitment to taking responsibility for your health problems and finding an effective solution that works for you. That message will be of value to all polio survivors with new late effects." **FREDERICK M. MAYNARD, M.D., OHIO**



"I understand that the physician at our major university is doing spinal taps on patients with post-polio syndrome and has found the polio virus active in these patients." **Name withheld**

I checked with the physician in question and he reports being "perplexed and amused at reports of what may be happening at our university. I am not presently nor have I in the past performed spinal taps on a routine basis for post-polio patients. I have not found active polio virus in those with polio weakness. If this individual was a patient of mine, then she may have misunderstood some of the data I discussed with her. This data suggests some antibody formation against polio virus in those who have been previously infected. This is a long way from believing that active virus is present." **Name withheld**



"When we spoke last you suggested that I call Carl Coelho, PhD, at the Gaylord Hospital in Wallingford, Connecticut. At that time Dr. Coelho was organizing the second phase of his research into post-polio swallowing and respiratory problems. This second phase was expanding to add vocal chord evaluation, to be done in conjunction with Yale Medical School, in New Haven.

"This three prong research project incorporates the three areas in which I have post-polio involvement. I believe I am their classic case.

"In January I spent two days in Connecticut. For my part I got the knowledgeable, impartial, objective second opinion that I was looking for. I believe that the research project got a classic case to add to their data bank. The vocal chord study was of particular signifi-

cance to me, because no one had looked at my vocal chords for 45 years. Not until I had a medical crisis was anyone interested. During the medical crisis I found that there was very little knowledge about vocal chords as a post-polio residual effect.

"It is now May. My evaluation by the group is still not 100% completed. I have been back in the hospital for another of life's detours. I have completed Dr. Coelho's requirements for the study. He wants me to have one last test to complete my needs.

"I would encourage members of the post-polio networks to participate in research projects whenever the opportunity presents itself. It is impossible to convey to you how helpful this was to me. It was just the right project at the right time. How can I say thank you for helping me to find them?"

Bernice, New Jersey

Dear Bernice: I am so glad you found the reference to Dr. Coelho helpful. I agree that survivors should participate in research projects when possible, but I also think each survivor should carefully consider any possible consequences of such participation.



"Even though I am retiring as medical director, I am continuing a special problems clinic at Sister Kenny Institute, and I anticipate moving ahead with some research that I had put aside when I was too busy. My title now is senior consultant and researcher at the Sister Kenny Institute and emeritus director. I want to send my best wishes to you and your staff and look forward to being active in some of the post-polio issues on a continuing basis but to a lesser degree."

Richard R. Owen, MD, Minnesota

Dear Dr. Owen: Thank you for all of your work on behalf of polio survivors. You are what Gini Laurie always referred to as R.D. — real doc.



"Thanks so much for all your help with our efforts for Polio Awareness Week.

"Both Governor Thompson and Mayor Norquist of Milwaukee designated Polio Awareness Week and sent proclamations. It was actually quite easy — they seemed glad to do it. We sent the press release to newspapers, TV stations, medical societies, hospital councils, and all other Wisconsin support group leaders. Maybe next year you could suggest to other states to try on a state and local level." **Jane, Wisconsin**

Polio Network News (Vol. 9, No. 1) asked readers about their experiences with a migratory rash and received the following:

"About a year and a half ago I developed a rash which started on my face and spread to my throat and chest. I thought perhaps I had developed an allergy to some

food but couldn't determine what food. The rash seemed to disappear but never completely. About six months ago it appeared as bright red blotches on my throat and chest and I decided to check with a doctor. He said it was giant hives, the cause was allergy, and gave me a prescription for periactin. Because I was too tired to stop at a pharmacy on the way home, I decided to wait until the next day to have it filled. But by then the rash was clearing up, and I never bothered with the prescription.

"As of now there is only faint evidence of rash but the itching never disappears completely even where there is no visible evidence of rash. I have noticed that it worsens whenever I am tired, and it is another warning indicator for me when I am overdoing. I have several such warnings before I realize that I am getting too tired. I don't seem to tire gradually, but suddenly get to the point where I can't do anything, even though just before that point I may have been feeling well." **Alline, Wisconsin**



"I was diagnosed as having post-polio syndrome in 1991. I am only mildly affected, mostly with fatigue in my right forearm and hand. For about a year I have had a hive-like rash. Sometimes it is like a cluster of small bright red spots that look like insect bites. Other times the rash is one or two very large two-four inch welts which appear about dinnertime and disappear the next day by noon. The rash is red and intently itchy and moves around in location from day to day. Sometimes it goes away for days at a time. My doctor feels it may be an allergy to aspirin, so I have switched to Tylenol for aches and pains. I am not on any other medication at this time, although I was on Mestinin for about one year." **Mary Joy, Illinois**



"I have post-polio syndrome and I get an itchy rash, mainly on my neck, but it appears on my arms and hands, too. It comes and goes, but responds well to hydrocortisone. I thought it might be a reaction to a drug I have to take, after malignancy — Tamoxifen.

"I do get another irritation, of a serious nature, that has never been explained. For some years now, when I injure myself, in any way, an irritation usually sets up in the wound. It always occurs between the third and tenth day after the trauma and is not on the skin, but deep under it. So no remedy applied to the skin reaches the itch. It sometimes occurs even after severe bruising. It occurs after surgery too, but in that case the degree of numbness from the procedure seems to mask it a bit. The degree of irritation was so severe, before I found a partial answer, that I felt I was not responsible for my actions.

"By trial and error I discovered that keeping the temperature of the wound down relieves it. This often

Continued on page 10

means keeping the whole body temperature down. It means using cool packs for at least a week until the problem disappears." **Joan, Dublin**



"I contracted polio in 1952 at the age of 12 and still wear one brace and use crutches (Amigo part time). I am dealing with a very itchy rash that seeps and gets crusty at its peak. It is on my weak leg below the knee and some on the foot. Although less severe at times, there are a couple of spots on the hands. The rash, which comes and goes, seems to be worse when the feet are down more, and cold weather seems to make it worse.

"Using hydrocortisone cream (2.5%) twice a day and keeping my feet elevated and warm seems to be the answer for me.

"No other members of my group have this problem."
Ethel, Michigan



"...an itchy rash, which was bedeviling several of your readers, was described. The prescription drug Valisone (betamethasone) might be the answer for some of them.

"For many years I have battled a similar rash. It started in my hair soon after I was hospitalized with polio in 1953 and spread, in fits and starts and patches, to my face, eyebrows, backs of ears and, at the farthest, to my shoulders. It turns the skin sort of flaky, which is a symptom not mentioned in the article. In every other way it matches the rash as described.

"I applied Valisone lotion for the first time about 1960 and it worked like magic. My skin was essentially clear within ten days, including a patch behind one ear that had been there for years. The rash keeps coming back, but controlling it is easy." **Craig, New Jersey**

Readers were also asked about reaction to Premarin. *A few ladies responded that they experienced allergic reactions. One reported breast swelling and extreme hair loss and, after switching to Ogen (estropipate), noted that it took her about a year to return to feeling normal. She also reported permanent red spots not unlike something her grandmother had, so she is not too concerned. Another lady reported large hives after two months. The physician did not think it was the Premarin "but I stopped taking it anyway and the hives went away. Now I take synthetic estrogen, not Premarin."*

New requests

"I have slept in an iron lung since 1955 and need some advice on what other lung users wrap around their necks. The skin on my neck is quite fragile. I have used: a folded diaper — soft but not enough pro-

tection; a strip of stockinette-wrapped foam — soft but loses too much pressure; stockinette over a layer of foam and a LIFECARE foam padded collar — leaky, wears out in three or four months."

Carol Purington, 104 Wilson Hill, Colrain, MA 01340 USA.



"Having contracted polio as an infant in 1923, I was left with one paralysed leg and had to rely on a heavy caliper and sometimes crutches for the next fourteen years. After many unsuccessful operations, one surgeon permanently stiffened my knee which enabled me to walk unaided and live a full and active life, until post-polio immobilised me last year, forcing me back onto crutches. The general prognosis was that I could never improve, but since July last one doctor has been treating me with acupuncture. Its main purpose is to reactivate the motor neurons controlling the affected leg muscles. Before starting acupuncture, my polio leg was numb and cold besides being too weak to take any weight. After ten months' treatment, not only is it much warmer and stronger, but I have very little pain, and that only at the end of days when I have walked too much. Lately I have managed to go up and down a few steps without any adverse effects.

"As a professional researcher and writer, I have been studying all possible material on post-polio and on acupuncture. Through the State Library in Sydney, I have located a few interesting medical reports from Asian countries, a reference to the use of acupuncture for polio individuals in an English medical book but nothing from the United States. Nor have I been able to find any other Australian doctors using acupuncture.

"I would be grateful if you could help me track down any results or medical opinions, positive or negative, on the use of acupuncture for post-polio."

Joan, New South Wales (*send responses to International Polio Network.*)



"I would like to hear from other polio survivors who would be willing to share the results of their Lyme AB immunoblot/Western immunoblot test." **Steve Kelly, P.O. Box 664, Huntington, NY 11743-0664.**



"I have been considering, and I repeat, considering, having two surgeries done and need information, if it is available. The first surgery is an abdominalplasty (tummy tuck) to tighten the muscles in the stomach/abdomen area as a way to add support to the back. The second is stomach stapling to limit the food intake for someone who continues to gain weight even though limiting calorie intake. Do you have any information, gleaned from others, on either of these surgeries and the possible detrimental effects or successes reported by others?" **Mona Hughes, 1632 Asher Lane, Orlando, FL 32803 USA.**

Many polio survivors are requiring new braces. International Polio Network is interested in expanding its list of bracemakers and would appreciate hearing from our readers regarding qualified and polio-experienced orthotists.



A recent review of the progress of the Americans With Disabilities Act (*In The Mainstream*, Vol. 18, No. 4, July/August, 1993), states that over 40% of the complaints filed were related to discharge from employment (Title I), and the current economic and employment environment is partially responsible.

However, employers have generally focused most of the effort on the hiring process, rather than on the needs of their current employees with disabilities.

The Equal Employment Opportunity Commission (EEOC) data shows that 11,760 charges have been filed with them, 48.6% based on alleged discriminatory discharge, and 21.9% based on reasonable accommodations.

International Polio Network would like to hear from readers who have, along with their employer, made reasonable accommodations on the job to assist with their late effects of polio.



International Polio Network continues to share names and addresses of families with children with polio. If you are not on the list and would like to network with others, please send your name and address to IPN.



Survivors interested in joining a new post-polio support group in the Pasadena, California area, please contact **Frances Barrett Kitrell**, 744 N. Catalina, Pasadena 91104 (818/791-3714).



"Your readers may be interested in getting a copy of excellent articles on Franklin D. Roosevelt that appeared in *Public Welfare* magazine, (Spring and Summer 1984). Copies of Part I and Part II are available from the American Public Welfare Assn., 1225 Fifteenth St., NW, Washington, DC 20005 (202/293-7550). Articles are \$2.75 apiece pre-paid."
Sharon, Texas

◆ **Power Tools**, a guide to forming a support group, was developed at the request of the organizers of the 1992 International Conference on Self-Help and Mutual Aid. To order this, eight-page publication, send \$3 (postage included) to SupportWorks, the Self-Help Clearinghouse, 1012 Kings Dr., Charlotte, NC 28283 USA (704/377-2055).



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CALENDAR

◆ **Post-Polio Syndrome: Become Your Own Medical Advocate**, Holiday Inn Southeast, Aurora, CO, September 10-12, 1993. Contact: Julia Beems, 303/233-1666, or Bev Holst, 303/423-1179, or 800/875-4732.

◆ **Copenhagen Post-Polio Conference**, Copenhagen, Denmark, September 23-24, 1993. Contact: Gertie E. Larsen, PTU (National Society of Polio and Accident Victims), Tuborgvej 5, DK- 2900, Hellerup, Denmark (45 3162 9000).

◆ **Conference on the Rehabilitation of the Late Effects of Polio**, Janske Lazne, Czech Republic, October 28-30, 1993. Registration information can be received from Statni lecebne lavme, 542 25 Janske Lazne, Czech Republic, Europe. FAX 04 39/942390.

◆ **Getting Well and Staying Well** sponsored by the American Academy of Physical Medicine and Rehabilitation, November 2, 1993, Tuesday, 1:00 P.M. to 5:00 P.M., Fontainebleau Hotel, Miami, FL. For more information contact: American Academy of Physical Medicine and Rehabilitation, 122 S. Michigan Ave., Suite 1300, Chicago, IL 60603 USA (312/922-9366).

◆ **Sixth International Post-Polio and Independent Living Conference**, St. Louis Marriott Pavilion Hotel, St. Louis, MO, June 16-19, 1994. Contact Joan L. Headley, International Polio Network, 5100 Oakland Ave., #206, St. Louis, MO 63110-1406 USA (314/534-0475 or FAX 314/534-5070).

◆ **NO PITY: People with Disabilities Forging a New Civil Rights Movement** is the first book to tell the history and ongoing struggles of the disability rights movement. Written by U.S. News & World Report editor Joseph P. Shapiro, the only reporter to cover disability issues full-time, *NO PITY* tells many of the personal stories that he uncovered in his five years of in-depth reporting. The book reveals a revolution in the self-perception of people with disabilities that has led them to assert and demand their rights. People with disabilities no longer see their physical or mental limitations as a source of shame or as something to overcome in order to inspire others. The new thinking is that there is no pity or tragedy in disability, and that it is society's myths, fears, and stereotypes that most make being disabled difficult.

No Pity (ISBN 0-8129-1964-5) by Joseph P. Shapiro is available from bookstores (Times Books, 201 East 50 St., New York, NY 10022 USA, May 19, 1993).

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