

POLIO NETWORK NEWS

International Polio Network

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G.I.N.I.

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

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Underventilation: A Warning

WARNING to all who were weaned from an iron lung back in the 1950's. If you have trouble sleeping, morning headaches, and feel tired and unjoyous, show this article to your physician.

By Richard L. Weiler, Columbia, MO
(Polio survivor)

Central Alveolar Hypoventilation Syndrome - my doctor's description of a condition which was slowly destroying me and of which I was alarmingly ignorant.

I am a polio survivor (1955) who relied on mechanical ventilation for approximately a year after the disease struck, six weeks in an iron lung and the remainder of the time in a chest cuirass or shell and a rocking bed. After this, it was decided that I could breathe adequately without mechanical ventilation and, at the age of sixteen, I began to cope with the severe paralysis which remained, a process which has taken a lifetime.

After six months at the Georgia Warm Springs Foundation, I returned home to Nebraska to complete high school. After that, college and law school at the University of Missouri, Columbia. Since 1968, I have been employed by the State of Missouri, currently with the Attorney General's office.

It is hard to remember when the first symptoms of breathing difficulties began to appear, but it was well before any public discussion of "post-polio syndrome." I began to experience difficulty in sleeping at night, I started having vivid dreams and sometimes nightmares, and I seemed to wake up often. This, of course, led to fatigue during the day.

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Underventilation: A Warning

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Six years ago, my local doctor became concerned about continued high blood pressure readings and I started taking blood pressure medication. Approximately four years ago, I woke up in the middle of the night with a tremendous ache in my chest and stabbing pains down the left arm. Fearing a heart attack, I was rushed into the emergency room of the local hospital. Tests disclosed no damage to the heart but my breathing difficulties at night were noticed. Upon my physician's advice, I started using the chest cuirass or shell for breathing assistance at night.

Although the chest shell provided some relief for the next several years, the problem started accumulating again. My sleep patterns became very erratic (I would sleep heavily for an hour or two and then spend the rest of the night awake or in a shallow dream stage), I had morning headaches, tiredness during the day (at times I could not keep my eyes open), and at times I was not mentally alert. Sinus conditions from allergies aggravated the condition and made life miserable. At times I would be so tired at the end of the day that I could barely speak audibly.

Finally, in the fall of 1987, a doctor suggested a sleep test. Results indicated that the symptoms were caused by a carbon dioxide buildup because of inadequate ventilation at night. The doctor recommended a return to the iron lung at night. He suggested that daytime use might be necessary also in the future.

This was a real shock for me. My health had reached a point where continued employment seemed in jeopardy. Now the doctor was telling me that the cure might also make it impossible to continue employment. I decided to seek a second opinion from someone more knowledgeable on post-polio prob-

lems. After soliciting information from various sources available to me, I decided to contact Dr. Oscar Schwartz, a pulmonologist in St. Louis. Dr. Schwartz called me to discuss my condition and followed up with a letter. As a result, I checked into a hospital in St. Louis in early December, 1987.

I have heard weight lifters say "no pain, no gain." That describes my five day stay in the hospital under the supervision of Dr. Schwartz. They took so many blood samples that I think I am qualified for a Red Cross pin. I was introduced to positive pressure ventilation using a nasal mask which promptly blistered my nose. However, the gain was tremendous. The first night I used the nasal mask and positive pressure, I slept better than I had in years. By the end of five days the nasal mask no longer felt alien and I was sleeping soundly through the entire night.

I now wake up in the morning refreshed with plenty of stamina for the entire day. The morning headaches have receded and the periods of mental fatigue have disappeared.

The change has been obvious to all those around me. For the first time in a long time, I am enjoying myself both at home and at work. Even the blood pressure problems have disappeared. After evaluating the situation, Dr. Schwartz discontinued all of the blood pressure medicine.

Any polio survivor who required ventilatory support in the past, or whose current ventilation system is not allowing sound sleep, should seek the advice of a knowledgeable medical specialist. If you are not sure who that might be, Gini Laurie at International Polio Network will provide you with the necessary information.

Reprinted from the Rehabilitation Gazette (Vol. 28, No. 2).

Ventilator Resources

For information about available respiratory equipment contact the following manufacturers:

Aequitron

Call 800/824-7203 and ask for the Customer Service Representative in your area or write: Aequitron Medical Inc., 14800 28th Avenue North, Minneapolis, MN 55447.

Bear Medical

Contact:

Bear Medical Systems
2085 Rustin Avenue
Riverside, CA 92507
714/788-2460.

Lifecare

Call the home office 303/666-9234 and ask for the name one of the 17 representatives in the U.S. or one of the 20 distributors in Europe, Scandinavia, Australia, and Asia.

A complete listing, both national and international, may be obtained by writing to:

Lifecare
655 Aspen Ridge Drive
Lafayette, CO 80026

Puritan-Bennett

Contact:

Mr. Terry Preston
10800 Pflumm Road
Lenexa, KS 66215-2198
913/469-5400

IPN Membership Renewal Notices

In April, IPN mailed renewal notices to individuals whose memberships are due this quarter. Renew by returning the card with a check for \$8.00 so you will receive the Summer Polio Network News (Vol. 4, No. 3).

IPN's 1989 Conference

IPN's Fifth International Polio and Independent Living Conference will be held May 31-June 4, 1989 at the Sheraton St. Louis Hotel, St. Louis, Missouri.

Abilities Expo-Midwest, a show devoted exclusively to products and services for persons who are physically disabled and aging, will be held simultaneous with the Conference at the adjacent Cervantes Convention Center June 2-4, 1989.

Planned conference sessions include the latest treatment and research findings on the late effects of polio, facts on aging with a disability or impairment, and discussion on legal rights and ethical issues of persons with disabilities.

Now is the time for input from polio survivors and health professionals. Contact the IPN office with your suggestions or concerns.

Support Group Leaders' Workshop

Training sessions at the June 3-5, 1988, polio support group leaders' workshop will include how to work with groups and health professionals, hints on writing newsletters, ideas for financing a support group, and suggestions for making adjustments to life changes.

Participants will be updated on the medical and research aspects of the late effects, the disability rights movement, and the work of G.I.N.I. Time will be allotted for the mutual exchange of ideas and discussion of the future goals of the network.

Polio Network News (Vol. 4, No. 3) will summarize the meetings. Workshop notebooks are available from International Polio Network, 4502 Maryland Avenue, St. Louis, MO 63108 for \$10 plus \$3 postage.

The Late Effects of Polio: An Overview

Gini Laurie, St. Louis, MO

Polio, the dread disease of the 1950s, was virtually eliminated in the United States by the vaccines and almost forgotten except by the survivors. The majority of those survivors, with zest and determination, achieved maximum rehabilitation and lived full and productive lives in their communities. In the past several years, however, as they have grown older, some have begun to experience the late effects of polio - pain, weakness, fatigue, and sleep and breathing problems.

The Center for Disease Control estimates that there are between 200,000 and 250,000 people in the United States who have residual paralysis resulting from polio. Studies by the Mayo Clinic indicate only about 25% of the survivors may experience the late effects.

The most commonly reported symptoms of the late effects are:

- o unaccustomed fatigue - either muscle fatigue or generalized body fatigue
- o weakness in muscle - both those originally affected and those unaffected
- o pain in muscles or joints
- o sleep problems
- o breathing difficulties
- o swallowing problems

Unfortunately, the late effects of polio are still not well known among many physicians and they are difficult to distinguish from arthritis and other degenerative disorders of muscles, ligaments, and joints. Survivors who develop these new problems may be told "It is all in your head," given

inappropriate prescriptions, or sent for expensive referrals. A frequent complaint is that their physicians do not appear to listen to them.

It is not difficult for polio survivors or physicians to become knowledgeable about the late effects. International Polio Network (IPN) through its conferences, workshops, and publications provides information and through its network of support groups provides people.

As a first step in prevention and treatment, polio survivors should undergo a general medical evaluation so one has a baseline from which to judge whether and to what extent one is experiencing the late effects. IPN, by publishing a directory of clinics and resource persons, can assist in finding an open-minded and understanding physician.

Early recognition, corrective procedures, and increased use of assistive devices can do much to alleviate pain and distress. A new brace may be needed, perhaps current crutches are damaging the arms or wrists, and a wheelchair should be used for shopping or traveling. Perhaps the arms are wearing out from propelling a manual wheelchair and a motor should be added or a change made to one of the new three-wheeled motorized chairs.

Most polio survivors have been pushing beyond their strength, trying too hard, refusing to give in or acknowledge weakness. They have been overcompensating, over-achieving and, possibly, overeating.

It's time for a long, honest look at one's lifestyle. It's time to think about moderation, conservation, and common sense. Expert polio physicians at the international

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polio conferences make the following recommendations:

- o don't overexercise; try swimming
- o don't overuse
- o rest when one is tired - stop for a 15- to 30-minute rest in midafternoon
- o watch weight gains
- o don't smoke
- o don't overindulge in alcohol
- o avoid narcotics
- o listen to one's own body
- o pace one's self; slow down

Of course, these recommendations are not easy to follow. But they will be much easier if one has the support and understanding of other polio survivors who are facing the same changes. There are more than 250 self-help polio support groups all around the world. They are an invaluable source of information about local physicians, therapists, bracemakers, and a helping hand with adaptation to change.

One can cope with the late effects of polio by using common sense, staying informed, and sharing with other polio survivors.

Editor's Note: IPN welcomes its many new members by including this overview of the late effects of polio.

MOVING??

Please send both old and new addresses to International Polio Network when you move. *Polio Network News* will NOT be forwarded by your post office.

New Post-Polio Clinics

The following clinics have been added to the 1988 Post-Polio Directory:

Buffalo, NY: Dr. Frederick McAdam, Erie County Medical Center, 462 Grider Street, Buffalo, NY 14215 (716/898-3218).

Cincinnati, OH: Dr. Richard Cremer and Dr. Peter Keebler, Department of Physical Medicine and Rehabilitation, University of Cincinnati Medical Center, 231 Bethesda Avenue, Cincinnati, OH 45267 (513/872-5195).

Reading, PA: Dr. Russell Youngberg, Reading Rehabilitation Hospital, RD 1 Box 250, Morgantown Road, Reading, PA 19607-9727 (215/775-8344).

Spokane, WA: Physical Medicine and Rehabilitation Department, Deaconess Medical Center, West 800 5th Avenue, Spokane, WA 99210 (509/624-9217) and Dr. Vivian Moise, Suite 454, Sacred Heart Doctors Building, West 105 8th Avenue, Spokane, WA 99204 (509/624-9217).

1988 Post-Polio Directory

The following corrections have been made in the 1988 Post-Polio Directory:

Birmingham, MI: Dr. Myron LaBan, William Beaumont Hospital, Barnum Health Center, 746 Purdy, Birmingham, MI 48009 (313/258-3700).

Tacoma, WA: Dr. Glenn Reynolds, St. Joseph Hospital and Health Care Center, 1718 South I Street, P.O. Box 2197, Tacoma, WA 98401 (206/591-6761).

Foot Problems Due to Polio

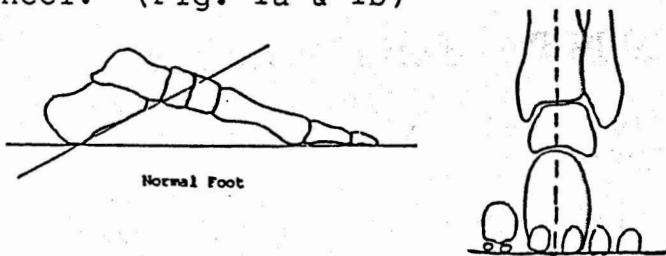
By Bruce Harley, D.P.M.,
Edwardsville, IL

Poliomyelitis is a neurological disease caused by a virus, which can result in partial or total paralysis of muscles. The polio virus damages the anterior horn cells of the spinal cord resulting in the inability of the nerve impulse to pass from the spinal cord to the peripheral nerves. The peripheral nerves and corresponding muscles then degenerate.

Polio may affect some, but not all, of the leg muscles. This partial paralysis creates a neuromuscular imbalance of the foot and ankle, often resulting in severe flatfoot or cavus foot (high-arched foot). The extent of the foot problem is determined by the pattern of muscular paralysis.

Anatomy of the Foot

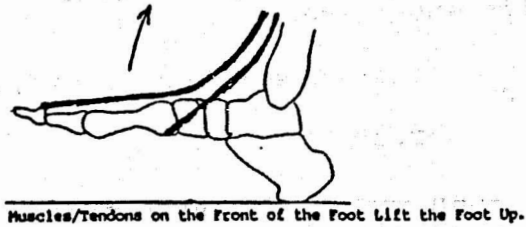
The normal foot is arched from back to front. The heel bone goes up and forward and the rest of the foot slopes down and forward. When viewed from behind, the heel should be vertical to the ground with the metatarsals perpendicular to the heel. (Fig. 1a & 1b)



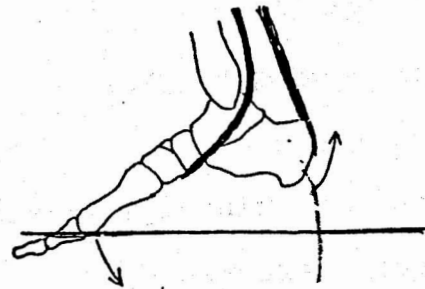
The heel should be vertical and the metatarsal bones are perpendicular to the heel.

Figure 1a & 1b

The function of the muscles and tendons on the front of the leg and top of the foot is to lift the foot. The function of the muscles and tendons on the back of the leg and bottom of the foot is to lift the heel and push the body forward. This muscular balance is commonly disrupted by polio. (Fig. 2a & 2b)



Muscles/Tendons on the Front of the Foot Lift the Foot Up.

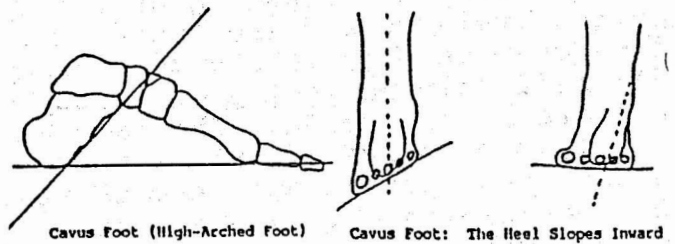


Muscles/Tendons on the Back of the Foot and Leg Lift the Heel and Push the Body Forward.

Figure 2a & 2b

Cavus Foot

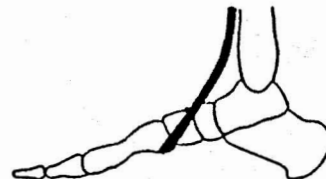
In cavus condition the foot has a high arch and the heel slopes inward. (Fig. 3a & 3b)



Cavus Foot (High-Arched Foot) Cavus Foot: The Heel Slopes Inward

Figure 3a & 3b

The tibialis anterior muscle lifts the inside of the forefoot more than the outside part. If the tibialis anterior is paralyzed, the inside of the forefoot drops down, creating an everted forefoot and an excessively high arch. When one stands on this type of foot, the entire foot tilts inward which makes walking difficult. (Fig. 4)



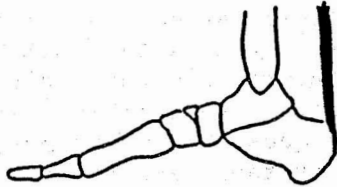
The Tibialis Anterior is Located in Front of the Ankle Joint and in the Arch. It Lifts up the Entire Foot and Lifts the Inside of the Foot More Than the Outside.

Figure 4

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The achilles tendon (gastrocnemius and soleus muscles) is the most powerful muscle for push off. It acts by pulling up on the back of the heel bone, lifting the heel during push off. If these muscles are paralyzed, the back of the heel moves downward, resulting in cavus foot. (Fig. 5)

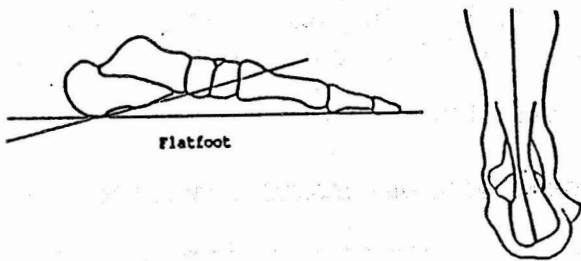


The Achilles Tendon Pulls Upward on the Heel and Creates Downward Movement of the Foot at the Ankle Joint.

Figure 5

Flatfoot

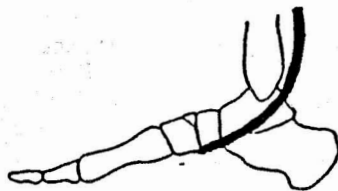
In flatfoot conditions the heel angles outward. (Fig. 6a & 6b)



Flatfoot: The Heel Angles Outward

Figure 6a & 6b

The tibialis posterior muscle holds the arch up while standing. Paralysis of the tibialis posterior results in a severe flatfoot. (Fig. 7)



The Tibialis Posterior Muscle is Located Behind the Ankle and in the Arch. It Functions to Hold the Arch up.

Figure 7

Editor: Cavus foot, flatfoot, and other foot problems due to polio can be solved in a variety of ways. Summer Polio Network News (Vol. 4, No. 3) will present articles with several solutions and would welcome your experiences and solutions.

Publications Available

The HIP Report

Help for Incontinent People, Inc. (HIP) was organized in 1983 to assist the 11 million persons who have bladder control problems. The HIP Report a quarterly newsletter is available for \$5.00 a year. Contact: HIP, Inc., P.O. Box 544, Union, SC 29379 or call 803/585-8789.

The Chronic Pain Newsletter

This bimonthly publication for people with chronic discomfort offers information on new and alternative therapies, research, publications, resources, and a forum for reader comments. The annual subscription rate for the Chronic Pain Newsletter is \$20. Contact: Box 1303 Old Chelsea Station, New York, NY 10011.

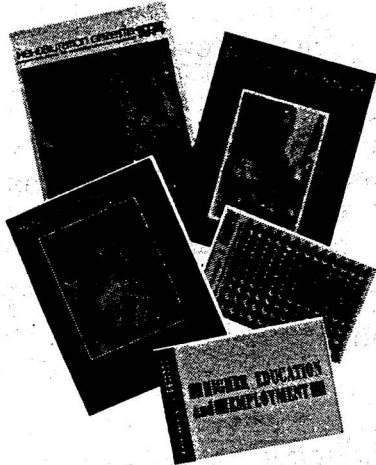
Spinal Network

Edited by Sam Maddox, Spinal Network is a wealth of information for people concerned with spinal cord injuries. The 374-page book is available for \$24.95 plus \$3 shipping from Spinal Network, P.O. Box 4162, Boulder, CO 80306. Telephone: 800/338-5412.

New Approach to Accessible Housing

A new document released by the U.S. Department of Housing And Urban Development (HUD), Adaptable Housing: Marketable Accessible Housing for Everyone, is a 77-page manual containing both general and technical information on designing and building adaptable units and is intended for disabled and non-disabled people, builders, developers, housing managers, architects, product manufacturers, and government and building code officials. Adaptable features identified are explained in relation to federal standards. To purchase the \$3.00 manual, call 800/245-2691 or 301/251-5154 in Maryland and Metropolitan Washington, DC.

Inventory Clearance Sale



In addition to the Polio Network News, Gazette International Networking Institute (G.I.N.I.), publishes the Rehabilitation Gazette.

Since 1958, this journal has been written by individuals with disabilities for individuals with disabilities. Each issue contains practical information that is still relevant today. The articles disclose, in a clear and descriptive way, solutions to some of the questions asked by persons with disabilities, as well as their families, friends, and concerned health professionals.

All available back issues have been organized into a topical index and the prices have been cut to the following:

Single Issue.....\$4.00 each plus \$1.00 postage
Two Issues.....\$3.25 each plus \$1.00 postage
Three (or more) Issues.....\$2.50 each plus \$1.50 postage
Complete Set (23 Issues).....\$60.00 plus \$8.00 postage

There is an order form on page 11.

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May 27, 1988. Team Approach to Post-Polio Syndrome for Health Professionals. Auditorium - Rancho Los Amigos Medical Center, 7601 E. Imperial Highway, Downey, CA 90242. Contact: Lorrie Mercer, RPT. 213/940-7111 ext. 7065.

June 3-5, 1988. Support Group Leaders' Workshop. Sheraton St. Louis Hotel, St. Louis, MO 63108. Contact: Joan Headley, International Polio Network, 4502 Maryland Avenue, St. Louis, MO 63108. 314/361-0475.

August 27, 1988. Post-Polio Syndrome: An Update. Kresge Auditorium, University of Cincinnati Medical Center. Contact: Sheila Stuckey, 595 Terrace Avenue, Cincinnati, OH 45220. 513/221-1720

November 3-5, 1988. National Conference on the Late Effects of Polio. L'Hotel, Toronto, Ontario, Canada. Contact: Shirley Teolis, Ontario March of Dimes, 660 Overlea Blvd., Toronto, Ontario, Canada M4H 1B6. 416/425-0501.

January 26-27, 1989. International Conference on Home Mechanical Ventilation. J.I.V.D. Service de Reanimation - Assistance Respiratoire Hospital de la Croix-Rousse, 93, Grande-Rue de la Croix-Rousse, 69317 LYON Cedex 04 - France Tel. 78.39.54.06.

May 31-June 4, 1989. International Polio Network's Fifth International Polio and Independent Living Conference. Sheraton St. Louis Hotel, St. Louis, MO. Contact: Joan Headley, International Polio Network, 4502 Maryland Avenue, St. Louis, MO 63108. 314/361-0475.