READING


The Post-Polio Syndrome: Advances in the Pathogenesis and Treatment edited by Marinos C. Dalakas, Harry Bartfeld, and Leonard T. Kurland; proceedings of the New York Academy of Sciences meeting (Bethesda, Maryland, April, 1994); (800/843-6927, Ext. 341 or 342); 412 pages; $100US plus shipping fee.

Home Mechanical Ventilation; proceedings from Fourth International Conference on Home Mechanical Ventilation (Lyon, France, 1993); Arnette Blackwell, Departement Librairie, 2 rue Casimir Delavigne, 75006 Paris, France, (+33 1.43.26.09.60); 384 pages; $65US.

Alternative Medicine: Expanding Medical Horizons; comprehensive report to the National Institutes of Health (NIH) from the alternative medicine community; Superintendent of Documents, P.O. Box 371954, Pittsburgh, PA 15250-7954, (202/512-1800 or FAX 202/512-2250); cite stock number 017-040-00537-7; 420 pages; $25, $3 per page.

New Directions in Supported Employment edited by Paul Wehman and John Kregel; VA Commonwealth University Rehabilitation Research and Training Center on Supported Employment, 1314 West Main St., P.O. Box 842011, Richmond, VA 23284-2011 (804/828-1851); manual or cassette; $12.95, Canadian residents add $2.50.


Directory of National Information Sources on Disability (NIS); National Rehabilitation Information Center (NARIC), 8455 Colesville Rd., Suite 935, Silver Spring, MD 20910, (800/346-2742), naric@capacccess.org (E-mail); $15.

1995 Disability Law Products and Services Catalog; Commission on Mental and Physical Disability Law, American Bar Association, 1800 M St., NW, Washington, DC 20036; catalog free.

Independent Living Skills Curricula (complete resources for skill training needs of people with disabilities); Access Living, 310 S. Peoria, Suite 201, Chicago, IL 60607, (312/226-5900, 1687 TDD, 2030 FAX); 25 workshop modules; $100 plus $9 postage.

Turtle Books is a series of 11 books, each telling a story about a young child with a disability; language age 3-7 years; Jason and Nordic Publishers, P.O. Box 441, Hollidaysburg, PA 16648, (814/696-2920, 814/696-4250 FAX); $9.95 each pbk, $13.95 hbk.

VIDEO

Sprint/Rothhammer has produced a video in their Wellness in the '90s series for polio survivors. The aquatic therapy video was written and demonstrated with the assistance of Robbie Leonard, PT, at Roosevelt Warm Springs Institute for Rehabilitation. The video presents options which survivors and therapists can use to individualize a program. The video costs $29.99 plus shipping. To order call (800/235-2156) or write Sprint/Rothhammer, P.O. Box 5579, Santa Maria, CA 93456.

Farming with an Upper Extremity Impairment and Improving Farmstead Accessibility are both available from Breaking New Ground Resource Center, Purdue University, 1146

Agricultural Engineering Building, West Lafayette, IN 47907-1146, (800/825-4264).

When Billy Broke His Head ... and Other Tales of Wonder, by Billy Golfus and David Simpson is an excellent documentary about Billy Golfus, a journalist, disc jockey, and writer living with a disability after head injury following a traffic accident. He gives a first person account and visits other individuals with disabilities. This Sundance Festival award winner was broadcast on many PBS stations on Tuesday, May 23rd. Many stations will show it at another time. Check your local listings. When Billy Broke His Head is distributed by Fanlight Productions, 47 Halifax St., Boston, MA 02130, 800/937-4113; purchase price $245, rental $50/day, S&H $9.

Several ADA materials are available in Spanish — 800/949-4232.

National Information Clearinghouse for Infants with Disabilities and Life-Threatening Conditions (joint program of Center for Developmental Disabilities at the University of South Carolina, Columbia, and The Association for Care of Children's Health, Bethesda, Maryland) — 800/922-9234 ext. 201.

In Touch With Kids (ITWK) is a network for kids (age 1-18) with spinal cord injury to keep in touch through phone calls and letters. Contact: National Spinal Cord Injury Association, 545 Concord Ave., Suite 29, Cambridge, MA 02138, 617/441-8500, 617/441-3449 FAX.


To receive a free copy of Save Food Dollars and Help Your Heart contact The American Heart Association, 800-HAUSA1.
Cardiovascular disease is the most common cause of death in the United States. A high proportion of the deaths could be prevented by reducing important risk factors for heart disease. Three important contributors are physical inactivity, high-fat diet, and smoking.

- Cigarettes kill 419,000 Americans each year — more than alcohol, heroin, crack, automobile and airplane accidents, murders, suicides, and AIDS combined. Most of these deaths result not from cancer, but from heart attacks.
- Cigarette smoking is the number one cause of cancer death in men. Lung cancer surpassed breast cancer as the leading cause of cancer deaths among women in 1987.
- Nicotine in smoke increases blood pressure, heart rate, the amount of blood pumped by the heart, and the blood flow in the arteries of the heart.
- Smoking is a major risk factor of peripheral vascular disease — the narrowing of the blood vessels that carry blood to the leg and arm muscles.

- Smoking reduces the amount of oxygen to the heart muscle while simultaneously making the heart beat faster (increasing its demand for oxygen).
- Smoking is the main cause of chronic lung diseases. See COPD below.
- Many studies show that second-hand smoke can have harmful effects on non-smokers. Sidestream smoke — smoke in the air from burning tobacco - actually has higher concentration of some harmful compounds than mainstream smoke.
- Smoking costs the U.S. $65 billion per year in health-care costs and lost productivity — that’s $262 per American per year.
- In the U.S., 1.5 million people quit smoking each year, but as many as 50 million adults continue to smoke. WHO currently estimates that there are 1.1 billion worldwide who are cigarette smokers.
- In the 25 years between 1955 and 1990, the percentage of American adults who smoke has declined from 42.3% to 25.4%.
- Over the past decade, there has been no significant decrease in smoking rates among youths in the U.S., but higher tobacco taxes in California have led to a drop in cigarette smoking; and in Canada, higher taxes have led to a decrease in smoking of almost 2/3rds since 1980.
- When cigarette smoking ceases the likelihood of developing cardiovascular disease declines rapidly. Risk is reduced within one year, and after ten years the risk is essentially that of a non-smoker for a person who smoked a pack a day or less.

STOP SMOKING RESOURCES

Calling It Quits, Smoking and Heart Disease, How to Avoid Weight Gain when Quitting Smoking, Cigarette Smoking and Cardiovascular Disease. Free from the American Heart Association, National Center, 7272 Greenville Ave., Dallas, TX 75231-4596, 800/242-8721, or your local American Heart Association.

Freedom From Smoking® For You and Your Family; Freedom From Smoking® For You and Your Baby; A Lifetime of Freedom From Smoking®, and In Control®: A Video Freedom From Smoking® Program. For price information contact your local American Lung Association.

If You Smoke ... Stop for Good. Free from the American Medical Association, 515 N. State St., Chicago, IL 60610, or its co-sponsor Marion-Merrell Dow, Inc., 800/362-7466.

WHAT IS COPD?

COPD, or Chronic Obstructive Pulmonary Disease, "refers to a problem with breathing air out from your lungs. If you have difficulty breathing 'used' air out of your lungs, not enough space is left for oxygen-rich air to enter your lungs."

"Until recently, most people who had COPD were grouped together and considered to have one disease. We now know that several different diseases cause this difficulty in releasing air from the lungs. Asthmatic bronchitis, chronic bronchitis, and emphysema are three of the major diseases that are known as COPD."

Save Your Breath America! by Thomas L. Petty, MD and Louise M. Nett, RN, RRT.

RESOURCES FOR COPD

Pulmonary Education and Research Foundation (PERF), P.O. Box 1133, Lomita, CA 90717-5133 (310/539-2295) has published three booklets on Essentials of Pulmonary Rehabilitation. Part I introduces the basic methods of pulmonary rehabilitation and methods of treatment. Part II focuses on medications and quality of life issues. Part III specifically addresses the future for patients with chronic lung disease. Single copies of each are available without charge.

PERF also has produced two videos on Pulmonary Rehabilitation; one for physicians and one for lay people. Single copies of each are available without charge.

Questions about lung disease? Call LUNG LINE®, 800/222-LUNG. Callers within Colorado dial 303/355-LUNG. LUNG LINE® nurses are available Monday through Friday, 8:00 a.m. to 5:00 p.m. Rocky Mountain time.

LUNG FACTS™, 800/552-LUNG, is an automated information service available 24 hours a day, seven days a week.

LUNG LINE® and LUNG FACTS™ are services of National Jewish Center for Immunology and Respiratory Medicine, Denver, CO. To receive a patient education materials list call 800/423-8891, ext. 1079 or 7700.
The Channel Tunnel, linking the United Kingdom and France, is now operating. For accessibility information contact European Passenger Services (EPS), EPS House, Waterloo Station, London SE1 8SE, United Kingdom (44 71 922 4499).

UK Care Ltd, The Old Mission Hall, Chipping, Herts SG9 0PQ (44 01763 273933, FAX 44 01763 273934) is a rental company supplying various types of wheelchairs, battery and self-propelled, and three- and four-wheel scooters for individuals vacationing in England.

Ireland's National Rehabilitation Board supplies information on accommodations and amenities for people with disabilities. Four guides are available: Guide to Accessible Accommodations in Ireland; Accessibility Survey of Tourist Amenities in Ireland; Accessible Survey of Restaurants/Pubs; Dublin — A Guide for People with Disabilities. Contact: NRB, 25 Clyde Road, Dublin 4, Ireland '01 661 4181).

Israel's Ministry of Tourism's 800 number for inquiries on travel to and within Israel, is 800/596-1199 or FAX 212/629-4368.

Canada's National Transportation Agency has published three guides: Improving Access for Travellers with Disabilities; Air Travel Accessibility Regulations; Complaint Guide for Removing Undue Obstacles to the Mobility of Travelers with Disability.

Contact: Accessible Transportation Directorate, National Transportation Agency of Canada, Ottawa, Ontario K1A ON9, Canada, (800/883-1813 or 819/997-6828).

Accessing Sydney is a 300-page access guide to Sydney, Australia. Phone 02-977-8653 or FAX 02-977-8238 or write DEB Services, P.O. Box 315, Manly, New South Wales 2095, Australia for international prices and to order.

Access Brisbane is available from Disability Services Section, Brisbane City Council, GPO Box 1434 Brisbane 4001, Queensland, Australia (07 225 4416).

Disability Bookshop, Twin Peaks Press, P.O. Box 129, Vancouver, WA 98666, (800/637-2256, 360/694-2462 or FAX 360/696-3210), has published several guides of interest. Directory of Accessible Van Rentals, $9.95 plus $3.00 S&H; Directory of Travel Agencies for the Disabled, $19.95 plus $3.00 S&H; Travel for the Disabled (A Handbook of Travel Resources and 500 Worldwide Access Guides) $19.95 plus $3.00 S&H; Wheelchair Vagabond, $14.95 plus $3.00 S&H.

The 1995-1996 Wilderness Inquiry Schedule is available. Contact: Wilderness Inquiry, 1315 5th St., SE, Box 84, Minneapolis, MN 55414, (800/728-0719 or 612/379-3858).

Airport Rent-A-Car at McCarran International Airport, Las Vegas, offers wheelchair accessible vans. For more information contact 800/785-8578 or 702/795-0800.

Access for Travel, Consultation and Training, Carol Lee Power, 1429 10th St., W, Kirkland, WA 98033, (206/828-4220).

The Travelin' Talk Network, 130 Hillcrest Plaza, Suite 102, P.O. Box 3534, Clarksville, TN 37043, (615/552-6670 or FAX 615/552-1182), has a Membership Benefits Program which includes discounts at participating facilities including Red Roof Inn, Days Inn and Hotels, Howard Johnsons and Ramada, etc.

New PBS Documentary on Polio: Filmmakers Want Stories

The Center for History in the Media, associated with The George Washington University in Washington, DC, is currently working on an hour-long documentary on the American experience of the polio epidemics of the early and mid-20th century. A Paralyzing Fear: Polio in America is scheduled to be shown on PBS in the fall of 1997. Producer Nina Seavey and her crew are in the scripting process ‘right now, and are looking for stories and artifacts which will help them recreate an America where town swimming pools were closed, parents’ hearts stood still when their children came down with a cold, and Birthday Balls, the National Foundation for Infantile Paralysis (March of Dimes), and poster children created national headlines.

This film will be a study of how American society responded to polio, and how fear acted as a catalyst for public action.

Memories are important to this production. The makers are looking for personal stories, and specifically visual memorabilia — personal photos or home movies, letters, posters, scrapbooks — which will help capture the national experience of polio. The makers request that a letter describing some potent memories, along with PHOTOCOPIES of any visual materials be sent to research assistant Roger Munter, The Center for History in the Media, The George Washington University, Rome Hall 407, Washington, DC 20052.

+++ Jackie Ellerbrock, Continental, Ohio, has started a family information and resource center for parents and children with special needs. Information is sometimes hard for families to obtain in this rural area. Send any information free of charge to Family Outreach, P.O. Box 497, Continental, OH 45831.
For individuals with disabilities interested in self-employment, there has been a lack of resources to obtain the support and assistance necessary to become entrepreneurs. One entrepreneur program, The Business Enterprise Venture (BEV) in Pittsburgh, Pennsylvania, was established by the Pittsburgh Blind Association in October, 1994 to serve individuals with a variety of disabilities, including vision impairment, quadriplegia, paraplegia, and muscular dystrophy. It provides an evaluation which examines entrepreneurial characteristics, assists in the completion of a business plan, and assists with locating and obtaining the necessary funding required for a business venture.

Steven Hanulik became aware of BEV and moved through the program quite rapidly. "In less than four months, I have been able to locate, finance, and purchase an established business. I have been significantly disabled by muscular dystrophy since the age of three. With the help of The BEV in locating information and reviewing potential opportunities, I was able to find a business that required minimal physical labor, but needed my skills as a manager and entrepreneur. After careful review of a Fox's Pizza Den franchise that was for sale, I decided to finance the purchase with a loan backed by my residence to avoid the high interest rates of a bank." Steven Hanulik, Owner, Fox's Pizza Den franchise.

Tim Knoebel has created several ideas for new assistive devices and has utilized the program to assist with patent efforts. "In July 1991, a diving accident rendered me a C-5 quadriplegic. In December of 1991, I was released from the rehabilitation center and it took me the better part of 1992 to come to terms with my disability. At this point, I did some serious soul searching about what to do with my life. I realized I would not be satisfied working for someone else, and, as it was a life-long dream of mine, I decided to start my own business. After determining the type of business, I started researching and corresponding with a few companies for potential future business relationships. Recurring health problems put me in the hospital from February through April of 1994. After returning home and a short readjustment period, I started to focus on my business again and met with limited success. As my business is in an entirely new field that I had no experience in, I had no business contacts to rely on and seemed to be spinning my wheels at times. In February of 1995, I was introduced to Pittsburgh Blind Association's BEV program. This has proven to be an invaluable resource." Tim Knoebel, Owner, QuadCepts.

Currently, Tim and BEV staff are writing a "prototype grant," which will supply Tim with the necessary funds to commercialize his ideas. The BEV program, funded by the Office of Special Education and Rehabilitation Services (OSERS), focuses on business management and business ownership for individuals with disabilities. As 65-70% of individuals with disabilities are either unemployed or underemployed, the self-employment alternative provides greater independence. Additionally, assistive technology has expanded the opportunities for the home-based entrepreneur.

For more information on BEV, contact Kathleen George, Pittsburgh Blind Association, 300 S. Craig, Pittsburgh, PA 15213 (412/682-5600).

Sign Of the Times

The U.S. Equal Employment Opportunity Commission (EEOC) has released Compliance Manual Section 902: Definition of the Term "Disability" which provides information and instructions for determining whether an individual has a disability as defined by the Americans With Disabilities Act of 1990 (ADA).

The Commission believes the language of the ADA, if left alone, could be too broadly defined.

To obtain copies of the guidance, write to: EEOC, Office of Communications and Legislative Affairs, 1801 L Street, N.W., Washington DC 20507.

Have you been denied treatment or referral by your HMO?

According to AARP Bulletin more and more Medicare patients are in HMO's and denials of treatment are increasing. "All Medicare beneficiaries have a right to appeal denial, but only 2% of all denials are appealed. However, more than 75% of those who appeal are successful." If you want to appeal a denial, write to your Social Security office, or to the insurance carrier whose name is on the notice of denial.

The People's Medical Society suggests there are two ways of resolving disputes with an HMO. First, file a complaint with the patient grievance committee. If that is not successful, contact your state's insurance department.

A recent article in Fibromyalgia Network offered these comments: Give the physician with the HMO a try. If you are not comfortable with your treatment, be persistent in asking for a specialist. If told no, ask for an explanation. Suggest it is good medical practice to get a second opinion. If no resolution is forthcoming, consider paying out-of-pocket to see a specialist, arranging ahead of time for the specialist to relay treatment options back to the HMO physician. Another tack if you like your HMO physician is to become knowledgeable yourself about treatment options and start requesting specific treatment options from the physician.
Margaret A. Nosek, PhD,
Center for Research on Women with Disabilities, Baylor College of Medicine, Houston, TX, writes "In December, 1993, my research staff and I spun off from ILRU and began the Center for Research on Women with Disabilities at Baylor College of Medicine. While we are still collaborating with ILRU on several studies related to independent living, our new passion is the long-neglected and critically important area of sexuality and health issues for women with physical disabilities.

"With funding from the National Institutes of Health, we have been doing a major national study of women with physical disabilities. More than 950 women responded to our national survey (half with disabilities, half without). You may have filled out this survey — THANK YOU! We received a lot of feedback from respondents that they were happy someone was finally asking these questions. While we are still analyzing all the information, a few messages are coming out loud and clear. The loudest — FRUSTRATION. The rate of marriage and sexual activity is considerably lower among women with physical disabilities than women without disabilities. Understandably, so is the level of sexual satisfaction. We are examining what correlates with these lower numbers, for example, self esteem, body image, work status, social stereotypes, use of orthotic equipment. We will know by the end of the summer how important such factors are. This is not to say that women with physical disabilities are not sexually active. Indeed, 31% of women with disabilities in our sample had children. So ob/gyns — look out, we're coming!

"Which leads me to my new soap box — access to reproductive health care for women with disabilities. I found that I am not alone in my long history of difficult experiences with ob/gyns. Women we surveyed reported physical barriers in doctors' offices (exam tables, scales, mammography machines) and lack of information on the part of physicians about how disability affects reproductive health as serious problems in getting good health care. I see two roads to solving these problems. First is to educate physicians about the ordinary health needs of women with disabilities. Right now, they receive almost no training on this in medical school. You would be surprised how many women told us their doctors treated them as if they had no need for reproductive health care. Second, and equally important, is training women with disabilities on how to work the system, what they need to maintain good reproductive health, and how to demand and receive the services they know they need.

"I have one more new passion — spirituality and rehabilitation. For me, living as a single, independent woman with a severe physical disability (spinal muscular atrophy) has posed many challenges. I regularly draw on my spiritual beliefs and disciplines to get through it all. I was invited to attend a conference on this topic at the National Institutes of Health. It was two days filled with lively discussions, mostly about the differences between religiousness and spirituality, and about how virtually nothing is known of the role spirituality plays in the lives of people with disabilities. If you would like to share your thoughts, please send them my way at Center for Research on Women with Disabilities, 6910 Fannin, Suite 310-South, Houston, TX 77030 (713/797-6282 voice and TDD, FAX 713/797-6445) e-mail mnosek@bcm.tmc.edu."

Jack Genskow, PhD, Professor, Human Development Counseling Program, Sangamon State University, Springfield, Illinois, reports he was on sabbatical for the 1994 Fall semester and did not teach last Summer. "It was great! My major project was writing a handbook entitled Consumer Involvement on Advisory Boards and Councils: An Issue of Uncommon Common Sense to be published by the Rehabilitation Research and Training Center at the University of Wisconsin-Stout, Menomonie, Wisconsin. I also was one of ten Institute on Rehabilitation Issues (IRI) scholars who wrote a monograph entitled Operationalizing Consumer Decision-Making and Choice in the VR (vocational rehabilitation) Process.

"At the Sixth International Post-Polio and Independent Living Conference, I won the drawing for therapy at Futures Unlimited with Ed Snapp and his staff in Columbus, Mississippi. Lil and I spent 14 days there in November as Ed's guests which included a place to stay as well as the daily treatments. Southern hospitality is indeed fine! The treatments included twice daily massages, pressure points, and quiet time suspended on slings in warm water tanks and pools, all done in a darkened environment in accordance with Ed's theories. Staff members were enjoyable to work with. I noticed some immediate benefits, but have not seen long-term gains. From what other participants said, none of whom were post-polio, people respond individually to the treatments and all were positive about the program."

After the 1994 G.I.N.I. conference Mary Westbrook, PhD, returned to the University of Sydney where she lectures to students in the Faculty of Health Sciences on the Psychology of Physical Disability. In March, Mary attended the 12th World Congress of the International Federation of Physical Medicine and Rehabilitation in Sydney and presented a paper on "Changes in post-polio survivors over five years: Symptoms and reactions to treatment." At a polio consumers forum held during the congress she presented "The hassles of living with post-polio: Some survival strategies."

She has recently contributed two chapters on health psychology entitled, "How social expectations differ for women and men who have become disabled" and "Coping with the late effects of early life disabilities." She is completing research comparing the experiences of mothers with disabilities (mobility and hearing impairment) with those of non-disabled mothers. Another project has compared attitudes toward disability

Continued on page 6
of mainstream Anglo-Celtic Australian society with those of Australians from Greek, German, Chinese, Arabic, and Italian backgrounds.

The most memorable aspect of the G.I.N.I. conference was her interactions with other participants. "I found myself acting in a much more extroverted and relaxed manner than usual and it struck me that it was like not being disabled. I had never realised the extent to which having a visible disability affects you when meeting another person for the first time. Although not consciously, your mind is wondering what assumptions are being made about you, whether the other person is uncomfortable with disability, etc. At G.I.N.I. almost everyone had had polio. It was a constant. I realised, this is how the non-disabled people must approach making new acquaintances."

Post-polio has forced Mary to give up typical gardening but she has just had a courtyard area with built up garden beds constructed which she can cultivate from her wheelchair. Mary Westbrook can be contacted at 29 Valerie Ave., Chatswood, N.S.W. 2067, Australia.

Susan Armbrecht is now the co-president of the Board of Directors of Services for Independent Living, the independent living center in Cleveland, Ohio. Susan has obtained new computer equipment and would highly recommend Drag and Dictate by Windows.

Polio survivor Nell Blaine's recent exhibit at the Fischbach Gallery, 24 W 57th St., New York, NY 10019-3935 (212/759-2345) was her 54th one-woman exhibition. A catalog of her recent oils, watercolors, and drawings is available postage paid for $7. The selections from her early work were also recently shown at the Tibor de Nagy Gallery, 41 W 57th St., New York, NY 10019 (212/421-3780).

Mona Hughes began writing a column entitled "Opening Doors" for the Orlando Sentinel in December, 1993. Her now-weekly column "covers about everything that relates to the condition of a human being with a disability. Sometimes the columns are strictly informational and sometimes they contain my opinions." In her recent column regarding Franklin D. Roosevelt, Mona writes "But anyone who has joined the ranks of the disabled can attest that it changes you inside as well as physically. You think differently about life and the priorities you hold so dear. "His disabling bout with polio must have given him far more understanding about life from the other guy's point of view. For that reason, his disability was important to his ability to govern the way he did and the choices he made."

Mona recently had a piece published in the Cape Cod Times. For samples of her work, contact Mona at 1632 Asher Lane, Orlando, FL 32803 (407/896-9904).

G.I.N.I. extends its thanks to the many friends who regularly contribute to our work.

We offer a special thank you to relatives and friends of the family of Joseph H. Howie who honored his memory by contributing to G.I.N.I. Joseph H. Howie was the father of polio survivor Polly H. Dawson of Madison, Mississippi and to friends and relatives of Bill Young, Ft. Smith, Arkansas, husband of polio survivor Joy Young, who honored his memory by contributing to the work of International Polio Network.

Contributions honoring loved ones are very special to us.

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5100 Oakland Ave., #206
Saint Louis, MO 63110 USA
An Encounter with Myofascial Release

Last March I traveled to Sedona, Arizona from rural Missouri to a training institute to learn the techniques of myofascial release taught by the physical therapist who developed the treatment approach in the mid-eighties, John F. Barnes. My reservations about being able to participate as I have considerable leg and hip weakness from polio in 1953 were dispelled by therapists from the Myofascial Release Treatment Center in Paoli, Pennsylvania. I was able to perform the releases we learned with no physical difficulty.

As I entered the large meeting room in a lovely resort nestled in the red rocks of Oak Creek Canyon, I wondered what I would learn that I could use as an occupational therapist working with young children with cerebral palsy and traumatic brain injury. Secondly, I hoped to learn how to work with my own tightness in my back and neck (the trapezius muscles and the long latissimus dorsi muscles), and perhaps, learn to relieve some of the joint tightness I have noticed in my husband who has arthritis.

Over the next four days, I learned how to “quieten down,” a Barnes term meaning to focus, and to provide myofascial releases with changing partners, most of whom were physical, massage, and occupational therapists. As we worked with each other, as both therapist and patient, I became aware of the wholeness of my own body, and how light pressure in specific places could relieve the stresses in my muscles.

Fascia is the connective system within our bodies, surrounding every muscle, joint, and even the individual cells; it is the covering of the brain that elongates to cover the spinal cord and all the nerves leaving the spinal cord. Our bodies require the fascia to move easily between the muscles and other structures facilitating smooth, unrestricted movements and protecting the delicate nerves and blood vessels. Over time, with the physiological and emotional stresses of our lives, particularly those of us with neuromuscular disabilities, the fascia may become tight and less fluid, causing significant restrictions. The result is usually pain.

Barnes compares the tightening of the fascial system to bailing wire around the nerves and blood vessels. And, tightness in one part of our body, since we are connected by this vast system of fascia, may be transferred to another part of our body, far from the site of the restriction. Headaches, temporomandibular joint (TMJ) pain, backaches, and diffuse pain in many places in our arms and legs may be the result of the fascial restrictions of our aging bodies.

“Assisting Persons with a Post-polio Syndrome,” is one of a number of articles by Barnes and other therapists in his extensive manual on the myofascial release techniques and craniosacral therapy. He feels that polio survivors respond well to treatment programs using myofascial release and neuromuscular reeducation. Long-term imbalances in our muscle length and strength cause stresses of overuse and microtrauma, and result in pain and decreased function.

Many post-polio survivors have used the fascia to support their bodies over the years and releasing some of the tissue with this therapy may cause loss of functional abilities, i.e., loss of support around the pelvis which stabilizes the hips can cause new problems with walking. So, a word of caution, when using myofascial release therapy, muscle reeducation and physical and emotional support must be provided by a trained physical therapist. As the releases are done with a minimal amount of pressure on the body, there is no pain or discomfort associated with the treatment.

For me, this was a new way to look at my own body. I was intrigued by the sense of wholeness that it provided as I considered my areas of tightness. During one of the releases on my neck, a cervical release, I felt my head move to one side as the therapist supported my head from behind, while I was lying on the treatment table. I then felt some quivering and movement near my shoulder blade as the trapezius muscle began to contract. As I was very quiet with my eyes closed, the feeling of the myofascial release was foremost in my mind. Wow! I was an active participant in the change in my body. For about five weeks after the training, the left side of my neck has been relaxed and flexible. I have begun to tighten up a bit so it is time to find a therapist who uses myofascial release in treatment.

I believe that myofascial release and craniosacral therapy may hold answers for us, and we can expect a reduction of pain and increase in movement. Being able to relax completely and trust the therapist who is providing the treatment are necessary for effective changes. Myofascial release is truly a holistic approach to healing, using the mind-body connection which we are now acknowledging is very powerful.

REFERENCE: Myofascial Release: The Search for Excellence (1990), John F. Barnes, PT and Rehabilitation Services, Inc., 10 S. Leopard Road, Paoli, PA 19301, $65.
Eighth Annual Rehabilitation Conference: Contemporary Rehabilitation Issues, University of Kentucky, Department of Physical Medicine and Rehabilitation, August 24-26, Radisson Plaza Hotel, Lexington, KY. Contact: Carol Percy, College of Allied Health Professions, University of Kentucky, 465 East High St., Suite 204, Lexington, KY 40507, 606/323-6459.

Promoting Health and Quality of Life for Polio Survivors, August 26, North Ridgeville Education Center, North Ridgeville, OH. Contact: Dave Livingston, Ohio Polio Network, 216-327-0366.


September Post-Polio Syndrome: Aging with a Disability, September 8-10, Holiday Inn Southwest, Denver, CO. Contact: Colorado Post-Polio Connection Support Group, 9112 W. 81st Lane, Arvada, CO 80005, 303/423-1179 or Mary Ann Hamilton, Denver, CO, 303/722-6945.

Conversation on Disability Issues II: Secondary Conditions and Aging with a Disability, September 13-15, Syracuse, NY. Contact: Department of Physical Medicine and Rehabilitation, SUNY Health Science Center, 750 East Adams St., Syracuse, NY 13210, 315/464-4783.

European Respiratory Society, Annual Congress, September 16-20, Barcelona, Spain. Contact European Respiratory Society, 60 rue de Vaugirard, F-75006 Paris, France.

Siouxland Post-Polio Network Conference, September 22, St. Luke's Medical Center, Sioux City, IA. Contact: Mary Kay Tevis, RN, 712/239-4202.

Post-Polio Information Days — 95, September 22-24, Montreal, Quebec. Contact: Post-Polio 95, 95 Arlington Ave., Montreal, Quebec, H3Y 2W5, Canada, Tel/Fax 514/932-6092.

OCTOBER International Symposium and Exhibition on Orthopedic and Paralysis Sequelae Rehabilitation, Beijing, China, October 16-20, Contact: Mr. Hejian, China International Conference Center for Science and Technology (CICST), 44, Kexue Yuan Nan Rd., Shuang Yu Shu, Hai Dian, Beijing 100086, P.R. China. Closing the Gap Conference, Microcomputer Technology in Special Education and Rehabilitation, Minneapolis, MN, October 19-21, contact Closing the Gap, P.O. Box 68, Henderson, MN 56044, 612/248-3294.

NOVEMBER American Academy of Physical Medicine and Rehabilitation Annual Assembly, November 16-20, Marriott's Orlando World Center, Orlando, FL. Many Voices, One Future, TASH (The Association for Persons with Severe Handicaps), November 30-December 2, Hilton Hotel and Towers, San Francisco, CA. Contact: TASH, 29 W Susquehanna Ave., Suite 210, Baltimore, MD 21204-5201.