HISTORY OF POLIO SUPPORT GROUPS

"The International Polio Network (IPN), the center of information on the late effects of polio, has maintained a network of polio survivors for nearly 30 years. IPN is the coordinator of support groups, the organizer of biennial international polio conferences and support group leaders' workshop." Since I moved to St. Louis in August and started to work with other polio survivors as the Director of the International Polio Network, I have been learning some of the fascinating history beyond those words in the brochure.

President Franklin D. Roosevelt probably started the first polio support group in 1921. He shared the Warm Springs hydrotherapy with children recuperating from polio.

For a short time after the 1950's epidemics, the "alumni" of the polio respiratory and rehabilitation centers created self-help support groups. Eventually, they all disbanded except two. The Los Angeles group exists today as an advocate for local ventilator users. The Cleveland respiratory center group was continued by Gini Laurie, a volunteer at the center whose two sisters and brother had died from polio.

In 1958 she started a publication, the Rehabilitation Gazette, a journal of imaginative, practical, and down-to-earth life experiences written by polio survivors for polio survivors.

This publication evolved into the Gazette International Networking Institute (G.I.N.I.), a national and international information center for people with all disabilities. G.I.N.I. seeks to promote positive attitudes and to dignify individuals with a disability.
LETTERS TO THE EDITOR

"I have acted upon the conference options offered, and it has given me the feeling of 'doing' rather than just 'enduring.' I have enjoyed the News for several years now, but it was the conference that woke me up to do something about myself."

Irene Canonico
Red Bank, NJ

"I would like to hear more about nutrition and holistic health suggestions from those familiar with these 'new age' techniques. I follow a healthful living pattern .... There are some basic rules that I could share with you and anyone else interested."

Maurice Stein
P.O. Box 298
Foremost, Alberta
Canada TOK OXO

WATCH OUR WORDS

Attitudinal barriers are influenced by and reflected in language. Unfortunately, many words in current use, left over from paternalistic, isolating, and pitying concepts, continue to perpetuate negative and dehumanizing attitudes.

The Rehabilitation Gazette has always used the words disabled/nondisabled, rather than ablebodied/disabled, to emphasize the importance of disabled persons by subtly realigning priorities.

The word handicapped lingers on in the names of many older organizations for the disabled and its use is too commonly accepted without questioning the implications of its meaning of being disadvantaged. Unfortunately, disabled people are infinitely more handicapped by society's attitudinal barriers than by their own disabilities.

Phrases such as "the disabled" and references to a person as a disability are dehumanizing. Instead of using "the disabled" say "people or individuals or persons with disabilities." Instead of "she is a polio" say "she had polio" or "she was disabled by polio."

Many commonly used phrases express a demeaning attitude and reflect small expectations. Instead of "wheelchair bound" or "confined to a wheelchair" say "uses a wheelchair." A wheelchair is a means of mobility, not a hindrance.

Under no circumstances is a person with a disability "a victim" or "afflicted by" or "afflicted with."

"Normal" should not be used to describe nondisabled people because it triggers the demeaning and inaccurate opposite, abnormal, to describe disabled people.

Even more demeaning and obnoxious are the words that imply that because a person is disabled, he/she is asexual, does not have the same sexual impulses, drives and desires, the same need to love and be loved.

Almost equally dehumanizing are words that put disabled people on pedestals by labelling us with super-human qualities, especially courage and goodness. We make mistakes, lose our tempers, laugh, frown, hate, love because we are the same as everyone else-human.

ED: Excerpted from Rehabilitation Gazette/80. Volume XXIII.
HISTORY OF POLIO SUPPORT GROUPS (continued)

Because it never ceased to maintain a living network of polio survivors around the world, G.I.N.I. was the first to notice and to publish information on the late effects of polio, and in 1981, to organize the first of its biennial international conferences.

Dr. Frederick Maynard, of the University of Michigan Medical Center, told the St. Louis Post-Dispatch in 1987, "Gini was the catalyst. If she had not held that first meeting, it is possible we might still not know about these effects. Eventually, we might have noticed that many post-polio people had problems, I guess. But when?

"I remember thinking at that first conference, 'who am I to talk?', I told them I didn't know what I was seeing in the handful of people in my clinic was typical or just odd cases. The audience said yes, they had the same symptoms, knew others with them. After that first meeting, I was convinced."

In 1984, G.I.N.I. published the Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors and was the catalyst for the first of two scientific conferences at Warm Springs.

During the 1985 conference, the longtime G.I.N.I. polio network was formalized into the International Polio Network (IPN), a supportive network of autonomous groups. The quarterly newsletter, Polio Network News, and the Post-Polio Directory of support groups and clinics were initiated for its members.

Subsequently, more than 200 support groups and over 50 clinics have been organized and many regional and local conferences have been held. The conferences have been organized by local support groups, often in cooperation with independent living centers, universities, hospitals, March of Dimes or Easter Seal. The conferences, just as the biennial international conference, educate health professionals and the general public and foster esprit de corps in the polio community.

The determination, creativity, and organizational ability of polio survivors have been the keys to the maturation of the network. Many leaders have developed outstanding state-wide organizations and systems of reaching polio survivors and health professionals.

In addition to coordinating support groups, which provide invaluable psychological support for individuals, the International Polio Network has organized several national projects including advocacy campaigns and a Program Circular documenting the late effects of polio throughout the Social Security Administration and initiated National Polio Awareness Week.

The past accomplishments of the polio network are impressive. The immediate potential of the International Polio Network is limitless. The pending problems of polio survivors and other persons with disabilities are real.

Finding solutions to these pending problems is possible if we learn from our past, coordinate our potential, and never lose the sharing of our humanity and the goal of dignity for all.

Joan Headley
Ten years ago the Pan American Health Association (PAHO), the Regional Office of the Americas of the World Health Organization (WHO) initiated the Expanded Program on Immunization in the Americas. This directive was aimed at measles, tetanus, diphtheria, pertussis, tuberculosis, and poliomyelitis.

New cases of polio are less than a tenth of the number a decade ago. But the incidence of polio is still too high in the Americas. El Salvador, Ecuador, Peru, and Venezuela all reported a higher incidence of cases this year.

Eradication of polio from the Americas by 1990 is dependent upon monies from UNICEF, Rotary International, the United States Agency for International Development, the Inter-American Development Bank, and the WHO/PAHO.

By treaty the U.S. pays 25% of the budget for the UN and the specialized agencies. Because of alleged irresponsible spending within the UN, the Kassebaum amendment in 1985 declared that no more than 20% should be appropriated unless we have more say in the spending of monies. This cutback affects WHO/PAHO even though their spending practices were not in question.

The goal of eradicating polio by 1990 is being adversely affected. Margery Dam, External Relations Officer for WHO, states, "Some other organizations reduce or withhold funds for political reasons and some monies are a one-time contribution. It is our responsibility to stay in until the 1990 goal is reached."

According to Rich Gilbert of the American Public Health Association, the funding for WHO/PAHO is in conference. Contact your representatives and ask their support in assuring the U.S. meets its obligations to WHO/PAHO in the Fiscal year 1988 (FY88) and the arrears for 1987.


**WRITING TO WASHINGTON**

When writing to your legislators, properly identify the bill or issue that concerns you. In your own words focus on the one timely issue. The letter, preferably on your stationary, should be legible, brief, and explain why you are writing. Be sure your facts are correct. Inaccurate information, as well as threatening comments, can cause alienation.

It is appropriate to ask for their position on the issue and remember to thank them.

For Representatives:
The Honorable (name)
U.S. House of Representatives
Washington, D.C. 20515

(Dear Congressman or Congresswoman ___________.)

For Senators:
The Honorable (name)
U.S. Senate
Washington, D.C. 20510

(Dear Senator ___________.)
WHAT IS A PHYSIATRIST?

Many people are unaware that there is a special branch of medicine which is specifically dedicated to the diagnosis and treatment of physical disability. PHYSIATRISTS are doctors who are certified as specialists in rehabilitation medicine by the American Board of Physical Medicine and Rehabilitation (PM&R).

Since World War II, with the tremendous advances in acute medical technology, many more lives have been saved and people continue to live despite major physical impairments. Having added years to life, some visionary members of the medical profession realized, that it was also important for doctors to become involved in adding life to those years.

And that is how PM&R was born in 1946 in response to the challenge to help disabled citizens reach their maximum potential. What is so special about these specialists? After completing medical school and obtaining an MD or DO degree, they study four more years and take two extra examinations, one written and one oral. And the purpose of this extra training is to make sure that physiatrists become patient centered rather than disease centered doctors, who will treat people with disabilities in a total life context.

Most physicians deal with threats to life. The physiatrist deals with threat to living - the physical and psychological disabilities which remain after acute medical/surgical treatment.

The physiatrist coordinates a team of doctors and allied health professionals in developing and carrying out a comprehensive treatment plan which extends beyond hospital walls into the patient's community, family, occupation, friends and ultimate life style.

The physiatrist's major successes come in small increments. Each breakthrough, however subtle, can change the life of a patient for the better.


FINNISH ASK TO TRANSLATE HANDBOOK

Eero Kuikka, Executive Director of SUOMEN POLIOHUOLTO, reports 10,000 polio surviors in Finland. With very little information available in their language, they have been using the Swedish version of the Handbook.

In requesting translation rights, Kuikka stated, "...the kind of information presented in the book would be of great benefit and would serve our members, the authorities as well as the general public."

IPN is delighted to expand its network of knowledge and people to Finland.

ACTION IN AUSTRALIA

Anna Young, 317 Glynburn Rd., Kensington Park 5068, South Australia, reports that, "things are starting to happen since I attended the Polio Conference in St. Louis....The Polio Welfare Association has appointed a sub-committee....I want to do something to help the polio people here."
I attended the Polio Conference in St. Louis last June, to present an orthotic design to stabilize the atrophied thigh tissue of the polio survivor in long leg bracing. Prior methods of controlling the thigh tissue have been no different for polio survivors, than the individuals with spina bifida, paraplegia, and arthritis. However, all these patients have thigh tissue with firm density unlike the polio survivor.

I found that many polio survivors were not ready for a thigh control design because of dissatisfaction with and lack of understanding of their knee and ankle components.

Let me explain some basics to brace-wearers.

As expected, the foot and ankle orthosis gives direct control of flail joints. This component causes "floor reaction" when the foot makes contact with the ground and influences the knee (Fig 1a).

When the ankle is controlled – either by bracing with adjustable joints or with contractures and fusions – an unstable knee results (Fig 2a).

If the ankle is not braced but allowed to move freely, up (dorsiflexion) and down (plantarflexion), the foot will respond with "flat foot" after initial contact is made with the floor and weight is applied. The knee remains stable due to hyperextension of the knee or back knee bias (Fig 1b). Back knee bias is progressive over the years if not braced. The lack of a heel lever allows walking, orthotically, with a free hinging knee joint.

Because of the unstablizing effect of a heel lever and flail knee musculature, the survivor should consider a brace with a locking type knee joint. This locked knee joint will make walking easier because of heel lever response (Fig 2b).

I feel brace-wearing polio survivors can and should learn some basic facts and terminology so they can be knowledgeable consumers.

If you have questions, please call or write:
Glenn Ham-Rosebrock
9258 Gardendale Street
Bellflower, CA 90706
213/862-7674 or 213/602-0729

NETWORKING IN ACTION

Linda Terrill, 2714 W. Keller, #1, Santa Ana, CA 92704, described her experiences with braces made by Glenn Ham-Rosebrock in the spring Polio Network News. Linda writes, "I received many letters from others with the same experiences...I am concerned that because we are such troopers, we keep going instead of listening to our pain. Glen taught me to listen and make decisions about my body."
SUPPORT GROUP LEADERS' WORKSHOP

June 3-5, 1988 is the weekend reserved for the Polio Support Group Leaders' Workshop. Once again the leaders will meet at the Sheraton St. Louis Hotel.

The Friday evening buffet and registration will be high-lighted with a slide show depicting the history of polio support groups. Bring scrapbooks, newsletters, and other articles from your support group to display and share.

Recognizing that all support groups evolve and have different needs, sessions will be varied. The program is in the developmental stage and ideas are welcome.

Planned speakers include W. Joseph Connolly, PhD., a licensed Counseling Psychologist and an Organizational Psychologist. Dr. Connolly is co-founder and co-director of Communications Center #1 in St. Louis. He has twenty years of experience designing and conducting leadership programs.

Eileen Connolly, PhD., has researched and worked extensively with the dynamics of self-conception. She is co-director of Communications Center #1.

Morton J. May, PhD., will also participate in the Saturday morning session. Dr. May, a clinical psychologist, has several years of experience in conducting workshops relating to stress management and effective group leadership.

The basics of newsletter writing will be explained by Kathy Holman. Kathy is the Director of Public Relations, Clayton School District, Clayton, Missouri.

Suggestions on how to work with health professionals will be presented by Roberta Simon, RN, of Polio Network of Illinois.

Finalized sessions and registration forms will be published in the next Polio Network News. IPN looks forward to your participation - most importantly your input.

PROGRAM IDEAS FROM YOUR SUPPORT GROUP NEWSLETTERS

Titles -
- "Caring for Your Care Giver"
- "Devices for Independent Living"
- "Weight Control and Nutrition"
- "Consumerism and Consumer Protection"
- "Handling Stress"

Speakers from -
- an independent living center
- a travel agency
- Weight Watchers
- a social security office
- a pain clinic

Specialists -
- a urologist
- a podiatrist
- a physical therapist
- a physiatrist
- a neurologist

Etc.-
- salad social
- free swim night
- Sweet Adelines
- potluck
- wheelchair show and tell

IPN MEMBERSHIP RENEWAL NOTICES

In mid-November, IPN mailed renewal notices to individuals whose memberships are due this quarter. Please renew by returning the card along with a check for $8.00 so you will receive the Winter 1988 Polio Network News (Vol. 4, No. 1) and the Post-Polio Directory - 1988.
CARCHAIR

Carchair is now available in the United States (VA approval is pending for both the chair and the system). The carchair system enables an individual to be lifted into either front seat area without any physical transfer. The individual remains in the chair throughout while the wheelchair locks into the car chassis to become the car seat.

Carchair is being adapted for several fullsized American cars (Gresham Driving Aids in Michigan has used a Mercury and a Buick), but the manufacturer prefers the Nissan Stanza wagon because of its dual-sliding doors and pillarless construction.

The 1000-pound capacity lift, run from the car battery, operates by push-button control. The carchair reverses to open door and hooks onto the system cone to be lifted. The carchair swings into the seat-wheel and automatically locks into position.

A carchair system advantage is that it enables persons to drive a regular car rather than a van, thus saving gasoline.

The carchair system includes a power lift and three models of wheelchairs - self-propelled, attendant-pushed, and electric - that are contoured to the body.

Economically, the carchair system plus car roughly equals van conversion costs, but the carchair provides a wheelchair. Persons with disabilities who are anticipating needing a wheelchair might be interested in investigating the carchair, BEFORE they purchase wheelchairs.

The following van conversion specialists are carchair dealers:

Advanced Mobility, Inc.
12555 Sherman Way, North Hollywood, CA 91605
818/982-1004

Driving Aids, Ltd.
215 Commercial St., Vallejo, CA 94589
707/553-1515

Driving Aids, Ltd.
2216-A Cemo Circle, Rancho Cordova, CA 95670
916/635-2765

Grayless Mobile Aids
1132 Basse RD., San Antonio, TX 78212
512/732-1216

Gresham Driving Aids
30800 Wixom Rd., Wixom, MI 48096
1-800/521-8930

Rainbow Conversion
6834 N. 25th Dr., Phoenix, AZ 85017
602/433-1994

Write the manufacturer, Carchair Ltd., Robin Callow, Station Rd., Industrial Estate. Hailsham, Sussex, BN27 2ES, England or call toll-free, 1-800/367-9291, but please remember to add 5 to 8 hours for time zones.

PUBLICATIONS AVAILABLE

Research and Clinical Aspects of the Late Effects of Poliomyelitis, edited by Lauro S. Halstead, MD, and David O. Weichers, MD, contains the proceedings of the Second Research Symposium on the Late Effects of Poliomyelitis held September, 1986 in Warm Springs, GA. Payment of $15.00 a copy must accompany order. Make check or money order payable to the March of Dimes and mail to: Materials and Supplies, March of Dimes, Birth Defects Foundation, 1275 Mamaroneck Avenue, White Plains, New York, 10605.

Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors, edited by Gini Laurie, Frederick Maynard, MD, D. Armin Fischer, MD, and Judith Raymond utilizes a practical dictionary format to relate information on such topics as aging and weakness, diet, exercise, frog breathing, hospitalization, misdiagnosis, oxygen misuse, sleep apnea, vaccines and ventilators. Send $6.00 to: G.I.N.I., 4502 Maryland Avenue, St. Louis, MO 63108. (Discount prices for bulk orders.)

International Ventilator Users Network (IVUN), edited by Judy Raymond, is a world-wide network of ventilator users. The experiences of polio survivors are invaluable for persons with high level spinal cord injuries, muscular dystrophy, ALS, and other neuromuscular diseases and for the new population of technology assisted infants and children. Send $5 ($15 for health professionals) to G.I.N.I., 4502 Maryland Avenue, St. Louis, MO 63108 to subscribe to this biannual newsletter.

VENTILATORS AND MUSCULAR DYSTROPHY

Ventilators and Muscular Dystrophy by Nancy C. Shock, MA, and Agatha P. Colbert, MD, discusses the availability and increasing use of mechanical ventilation for persons with Duchene muscular dystrophy that is changing the prognosis for the life expectancy of the disease. Health care providers, community service workers, and family members review longterm mechanical and technical management, as well as psychosocial and ethical issues. Send $6.00 to: G.I.N.I., 4502 Maryland Avenue, St. Louis, MO 63108. (Discount prices for bulk orders.)

Audio and Video Tapes of G.I.N.I.'s Fourth International Polio and Independent Living Conference June 4-7, 1987. Eighteen audio and video (VHS and Beta) tapes are available. Audio tapes are $7 and video tapes are $15.00 ($1.50 for postage and handling). Write IPN, 4502 Maryland Avenue, St. Louis, MO 63108 for an order form.

TAX DEDUCTION FOR BARRIER REMOVAL

Polio support groups wishing to promote business accessibility in their communities may request a booklet recently published by the Paralyzed Veterans of America, Inc.

The PVA is campaigning to inform businesses how to use the barrier removal tax deduction. Section 190 of the Internal Revenue Code, as renewed by the 1986 Tax Reform Act, allows businesses to take a deduction up to $35,000 annually for making approved modifications. Requests for the free "Design Guidelines Qualifying for the Tax Advantages of Section 190" can be made by contacting Jean Jones, 405/521-3756 or 1-800/522-8224.
Susan S. Suter, a polio survivor, is the Director of the Department of Rehabilitation Services in Illinois. This agency, known as DORS, employs 2,044 people who work throughout 50 state offices serving people with disabilities. Suter is a nationally recognized spokesperson and advocate for the rights of people with disabilities.

The National Conference of Governors selected her as this year's recipient of the Distinguished Service Award, an award given annually to the nation's top state employee. On October 17, in Columbus, Ohio, she joined four other outstanding individuals with disabilities from across the country as one of this year's inductees into the National Hall of Fame for Persons with Disabilities.

In February she was selected by Glamour Magazine as one of ten "Outstanding Young Career Women" in the nation. She also has been a guest on "Hour Magazine."

Disabled at the age of two with polio, Suter was prevented from attending regular first grade due to an inaccessible stairway to her neighborhood school. Today Susan holds a degree in clinical psychology and directs DORS.

Susan lives in Springfield with her husband, Carl and 7-year-old son Josh.

THE ONE SHOE CREW

Anyone desiring a partner to share the cost of shoes, may register with The One Shoe Crew. There is a $2.50 fee for registration as well as one when a partner is found.

To register, or for further information, please write, and include a stamped, self-addressed envelope to: The One Shoe Crew, 86 Clavela Avenue, Sacramento, CA 95828.

POST-POLIO DIRECTORY AND SUPPLEMENT

The 1988 Post-Polio Directory is now being compiled at IPN. Please check your 1987 Post-Polio Directory and the Supplement. Send any additions, corrections, or deletions no later than January 15, 1988 to IPN, 4502 Maryland Avenue, St. Louis, MO 63105.

Please make the following changes in the Supplement:

CALIFORNIA
*Mary Marks
17155 Bullock
Encino, CA 91316
818/344-3722

COLORADO
**Capron Institute for Rehab. at Penrose Hospital
Terry Struck, MD
P.O. Box 7021
Colorado Springs, CO 80933
303/630-5789
SUMMARY OF A RECENT POST-POLIO ARTICLE


Patients who had acute poliomyelitis 30 to 40 years ago may develop new symptoms, the most common being fatigue, pain, weakness, and atrophy. A subcategory of the post-polio syndrome (PPS) is the post-poliomyelitis progressive muscular atrophy (PPMA) which is manifested by weakness, atrophy, and fasciculations. When weakness does occur, it more often occurs in previously affected muscles, but previously unaffected muscles may also be involved. The course of the disease is one of slow very slow progression. However, both EMG and muscle biopsy studies do not differentiate asymptomatic (no new weakness) from symptomatic (new weakness, PPMA) post-polio patients, and no diagnostic test findings can be considered pathognomonic for PPS or PPMA at the present time. Numerous etiologic theories are discussed to suggest avenues for future investigation. Patient management is briefly reviewed.

PHYSICIANS' PACKET

"My physician never heard of the late effects of polio."

To help you educate your physician, the International Polio Network has prepared a packet of information that will be sent, with your compliments, to your personal physician.

The packet includes:
* the Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors
* a four page selected listing of polio resources
* a professional summary of the late effects of polio by the National Institute of Handicapped Research
* the agenda of our last conference
* a letter naming you as the donor and stating the purposes of IPN

Please send the Physicians' Packet to my personal physician:

_________________________________________________________________________

I enclose $7 to cover the cost of copying and shipping.

_________________________________________________________________________
1987-1988 CALENDAR

December 11-12. Post-Polio Conference for Health Professionals. Tufts New England Medical Center, Boston, MA. Contact: Pat Andres, RPT, NEMC, 750 Washington St., Boston, MA 02111. 617/956-5846.


April 14-16, 1988. Late Effects of Poliomyelitis and Chronic Underventilation. Sports Center of the Technological University in the Olympic Park, Munich. Contact: Uwe Frehse, Westendstr 93, 8000 Munich 2, West Germany.


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.