

POLIO NETWORK NEWS

International Polio Network

4502 Maryland Avenue
St. Louis, MO 63108 U.S.A.
314/361-0475

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.

Annual Membership:
\$8.00 (USD* only) for polio survivors.
\$15.00 (USD only) for health professionals.
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*U.S. Dollars only

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Joan Headley

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Winter 1989 ■ Vol. 5, No. 1

NATIONAL POLIO AWARENESS WEEK

International Polio Network is working with several congressmen who will introduce the following proclamation declaring the week of May 29-June 4, 1989 as National Polio Awareness Week, focusing on the Fifth International Polio and Independent Living Conference in St. Louis.

A resolution commemorating the week of
May 29-June 4, 1989 as
NATIONAL POLIO AWARENESS WEEK

WHEREAS there are an estimated 300,000 polio survivors in the United States today, of whom as many as 70,000 may experience polio's late effects; and

WHEREAS awareness about the late effects of polio is beginning to spread to the health care community and to the general public; and

WHEREAS polio is still endemic in the Third World and poses a threat to unimmunized travelers; and

WHEREAS Rotary International has provided financial and humanitarian assistance to help eradicate polio in developing nations; and

WHEREAS the International Polio Network, in an effort to call attention to the recurring health needs of the survivors of polio and to provide accurate information concerning the late effects of polio, will bring together national and international experts on post-polio problems in Saint Louis during May 31-June 4, 1989; now, therefore be it

RESOLVED by the House of Representatives (the Senate concurring) that the week of May 29-June 4, 1989 be hereby designated as NATIONAL POLIO AWARENESS WEEK to focus attention on the late effects of polio; and be it further

RESOLVED that a copy of this resolution be transmitted to the International Polio Network at its meeting and to Rotary International, Chicago, as a reflection of our respect for their work in this important area.

Psychological Implications of the Late Effects of Polio

By Michael A. D'Anton, Ph.D.,
Rockaway Borough, NJ

Somehow the Ph.D. after my name is supposed to give me the answers to the emotional consequences of the late effects of polio. My years of training and practice in rehabilitation psychology are mitigated by my relationship with my wife, father, and aunt, all of whom contracted poliomyelitis at an early age. My research into poliomyelitis was briefly halted by a professor who asked me, "Where did you get this paper--one of your fraternity brothers? People don't get polio anymore." He was totally unaware of the number of new cases of polio each year in the world and the late effects of polio.

Candidly, my belief was questionable since my wife led a very active and aggressive life as a physical education teacher, swimming coach, and later, a physical therapist. My father and aunt's complaints were attributed to "old age." My mother frequently told my father to "push" himself. Reactions by our family to his physical complaints lacked empathy and his symptoms were ignored or denied.

As my wife's physical symptoms became more exacerbated and her physical activities became more limited, I realized that we were all very wrong and decided that not only as a rehabilitation psychologist, but as a husband, son, and nephew, I needed to know as much as I could about the physical limitations and psychological sequelae of these late effects of polio. I was successful in finding information about the former, but frustrated in my attempts to discover knowledge about the latter. As a result, I had to turn to sourcebooks on other conditions and integrate information from other patients.

As with all disabling conditions, the most prevalent symptom is fear which in most cases is dealt with by denial. Frequently, survivors will explain their initial physical symptoms as part of the normal aging process. As the physical symptoms progress, however, the typical symptoms of depression, anger, fear, frustration, nightmares, and in many cases, a reliving of the original onset of the illness appear.

For those individuals who entered physically demanding careers and activities to verify their wellness, the late effects of polio are a devastating blow to their identity and challenging identity questions are raised.

For those individuals who were segregated during their illness and as a result, developed feelings of detachment and alienation, the late effects exacerbates many of these symptoms, contributing to marital and family dysfunction. Psychological symptoms which are a marked contrast from the survivor's normal way of functioning are difficult for family members and friends to comprehend particularly when the course of the late effects is unknown.

Family members have accused individuals of being lazy, unmotivated, and distant; medical doctors have misdiagnosed survivors or not made the connection between histories of polio and current physical complaints. As a result of this lack of support, feelings of self-doubt and questions concerning sanity are raised.

TREATMENT IMPLICATIONS

Rehabilitation psychologists are faced with a variety of issues in treating individuals with the late effects of polio. A strong denial mechanism is usually the first problem encountered.

Education is a must at this juncture to alleviate fears, provide recommendations to diminish the physical effects, and acquaint family members with the possible course of the late effects. Support groups and polio information clearinghouses are excellent resources. Survivors, families, and rehabilitation professionals have reported that in many cases, diagnosis, education, and reassurance was often enough to dispel and negate the concerns.

While support groups typically deal with current difficulties, individual and family counseling supplements the work of the support groups. The psychologist can broach a variety of issues which might be uncomfortable for the survivor to deal with in a group.

Individuals need to deal with the symptomatology normally associated with post-traumatic stress disorder. Current problems that re-introduce feelings associated with the original trauma are more efficiently dealt with in individual sessions. The rehabilitation psychologist creates an atmosphere of trust and unconditional acceptance.

This therapeutic process allows the individual to deal with those feelings tied to the onset decades ago. Unresolved issues, including the anger at being isolated from one's family, as well as familial and societal attitudes toward polio and the survivor, appear to be more efficiently handled in individual sessions.

Family counseling serves as a basis for not only education but communication concerning those fears typically associated with the loss of physical functioning. The stress and strain placed on a relationship is diminished by communication, understanding, and a development of realistic family goals and expectations.

Altered family roles and patterns require discussion to ensure that both the survivor and the families do not feel victimized. Typically, marital relationships were developed on perceptions which are now changed. As expected, family dysfunction and divorce have developed. In some cases, however, statistical data on the rate of divorces as compared to other populations does not exist. Divorce heightens the survivor's negative feelings, and the survivor feels isolated again, replicating the original removal from loved ones.

Vocational rehabilitation can assist those individuals unable to continue in their present occupations. As with all vocational evaluations, a determination of transferability of skills can minimize retraining, alleviate the loss of self-esteem, and diminish the feeling that all that was gained is lost.

A referral to a recreation therapist will assist in developing leisure activities, where the late effects have caused a curtailment of a formerly active life.

Finally, dietary and exercise programs are best handled by referral to a physiatrist, physical therapist, or dietitian. Survivors feel that they have the best handle on these issues and frequently resist referrals. Any move to engage therapists frequently arouses fears that the late effects are progressing. This is one further issue that the rehabilitation psychologist has to negotiate. But once again, in many instances, education is enough to alleviate many fears.

Michael A. D'Anton, Ph.D., is a consulting psychologist at the Rockaway Professional Center, 171 West Main Street, Rockaway Borough, NJ 07866.

Vocational Rehabilitation: Still a Valuable Resource for Polio Survivors

Delbert O. Lewis, Little Rock, AR

In the early 1950's a small rural Arkansas town experienced 13 cases of acute poliomyelitis. One child died with the remainder of us sustaining varying degrees of permanent disability. In a poor agricultural environment with no available community services, it was an epidemic by anyone's definition. There were just too many of us for the March of Dimes to help.

Fortunately, as we neared high school graduation and long before there was such a thing as the "right to an education" and "mainstreaming"--we were told about a state agency that might be able to help "people like us." An appointment was made with a counselor at the vocational rehabilitation agency and that was the beginning of our lives as educated, productive, taxpaying, independent citizens.

Vocational Rehabilitation (VR) is still alive and well in every state and U.S. Territory plus the District of Columbia. It is available to assist eligible polio survivors with employment, vocational, and independent living issues.

ELIGIBILITY

Unlike Supplemental Security Income and the Social Security Disability Insurance program, vocational rehabilitation is not an "entitlement" program. Polio survivors, as all applicants with disabilities, first must be determined "eligible" for VR services by an agency counselor. By law, no physician or other entity can certify eligibility for services.

The individual must have a medically documented physical or mental impairment, the individual's impairment must be a substantial

handicap to employment, and the individual must require some approved service the VR agency can provide which will, in all probability, enable the client to gain, retain, or regain productive employment.

All three eligibility criteria must be met. A minor limp would not be a vocational handicap to most college graduates. Patients with terminal illnesses seldom have vocational potential. Persons over retirement age 65 would normally not be eligible for VR services.

An Arkansas Division of Rehabilitation Services brochure states, "The [eligibility] process begins with a complete physical examination and, in some instances, psychiatric and/or psychological evaluations. The examination and evaluation are necessary to determine the extent of your disability, and to help plan your rehabilitation program and your life thereafter."

In situations where vocational potential cannot be immediately determined, as is frequently the case with the unpredictable late effects of polio, the counselor may place the client in "extended evaluation" for up to 18 months. Almost all appropriate regular VR services can still be provided during this time.

In situations where clients are certified with very limited or no vocational/employment potential, some "independent living" type services through an Independent Living Center or similar community service may still be available. These options should always be discussed with the counselor in cases where immediate employment/vocational potential is questionable or if the client is "too severely disabled" to benefit from VR services.

Once eligibility is established, the counselor and client will together arrive at an Individualized

Written Rehabilitation Program (IWRP). This is the detailed schedule of goals and objectives of the client's rehabilitation program. The amount of time needed to complete a VR program is very flexible and dependent on such factors as the extent of the client's disability and the amount of personal involvement and commitment of the client. The amount of time it takes to complete preparatory educational and training activities such as a four-year college education or six-month vocational-technical course is also a factor.

SERVICES

The exact services necessary to achieve the goal of productive employment also vary greatly from client to client but are always listed in the IWRP. Services can include 1) diagnosis, 2) counseling and guidance, 3) physical restoration to remove or substantially reduce the individual's disability as a handicap, and 4) financial assistance.

Eligible clients may receive financial assistance for the purchase of initial tools or equipment, licenses or supplies for self-employment, job placement services, schooling and training, supported employment, any rehabilitation engineering needed to plan and design means of access to the home or work place (which can include modifying tools and equipment to make them more usable by persons with disabilities), services to family members if essential to the completion of the rehabilitation program (such as homemaker services, group counseling, day care services, foster family care, family planning and housing services), and various miscellaneous services including books and training materials, payments to cover meals, shelter, clothing, health maintenance, and related services.

Federal law and regulations require that VR clients first use any

"similar benefits" for which they may be eligible, such as Medicaid, Medicare, Worker's Compensation, or private insurance as well as any available family resources.

If the individual and family lack the resources to pay for services, then the state vocational rehabilitation agency may pay all or part of the costs. Many states have established a "financial needs" test. This helps ensure that limited resources and funds are wisely spent.

SUGGESTIONS FOR POLIO SURVIVORS

If polio survivors are unable to continue in their jobs or careers, they should apply to the state VR agency to secure the necessities to continue or regain employment or to become qualified to successfully start a new job or career. These services frequently include advanced college education or v-tech programs or the purchase of any equipment now needed in order to become or remain independent and productive.

Some states, including Arkansas, have sent "alerts" to their VR field staff to inform them of the disability of the late effects of polio. However, polio survivors should not be surprised if a field counselor is not informed on the issue. It would be wise to take some literature about the post-polio disability to the counselor prior to establishing eligibility.

Also, many local medical consultants providing diagnostic examinations/evaluations and advising the counselor on eligibility are likely to be uninformed on polio issues.

Survivors will find it helpful to take copies of personal medical documentation along with the newest medical research articles about the late effects of polio to all interviews. However, DO NOT take only consumer or newspaper articles as

(continued on next page)

Vocational Rehabilitation

(continued from page 5)

some professionals are unlikely to pay much attention to them.

A good work-up by an informed family physician or a summary of medical information developed on your case by a post-polio clinic will help support the application for services and help determine eligibility.

In some cases, if knowledgeable local medical personnel are unavailable and long distance travel is necessary to secure appropriate services, VR can pay for evaluation or treatment at a polio clinic along with associated travel and attendant services costs.

If a survivor's health later deteriorates and the individual applies for SSI or SSDI disability benefits, the accumulated VR medical and vocational reports can be invaluable in substantiating the claim. The state agency adjudicating SSI/SSDI claims for the Social Security Administration reviews all cases for possible referral to the VR agency. So it is important to inform the SSA District Office and the disability determination agency if the survivor previously has (or has not) been served by the VR agency.

If a survivor is a former VR client and has unsuccessfully attempted to remain employed or regain productive employment with the assistance of the VR agency, that documentation will significantly substantiate the claim for benefits.

SUGGESTIONS FROM A POLIO SURVIVOR

It is critically important to remember that you will be developing a plan for the rest of your life, with the support and assistance of the state vocational rehabilitation counselor. YOU ARE IN CONTROL OF YOUR OWN PROGRAM--NO ONE WILL MAKE THE DECISIONS FOR YOU NOR FORCE YOU INTO ANY DIRECTION YOU THINK IS

HARMFUL OR LESS THAN HELPFUL IF YOU ARE INFORMED, EDUCATED AND/OR ARE APPROPRIATELY ASSERTIVE WITHOUT BEING OFFENSIVE. You must have a fairly good idea of what goals to work toward. Most of you have been living independently and productively in the "mainstream" long before the concept was ever dreamed of by non-disabled parents and new "advocates." Taking charge of your future now should not be an exhausting exercise.

Delbert O. Lewis, a polio survivor who uses an electric wheelchair, is a Certified Rehabilitation Counselor employed as a Planning Specialist with the Arkansas Division of Rehabilitation Services, Department of Human Services, Little Rock, AR.

For more information about the services of VR, contact your state's office of vocational rehabilitation.

Personal

Gini Laurie, founder and chairperson of Gazette International Networking Institute (G.I.N.I.), had major surgery in December to remove a cancerous tumor from her esophagus. She is recovering at her home 4502 Maryland Avenue, St. Louis, MO 63108. Gini greatly appreciated the many thoughtful cards and flowers she received during her stay in the hospital.

Rehabilitation Gazette

Publication of the Rehabilitation Gazette (Vol. 29, No. 1 & 2), edited by Gini Laurie, has been delayed. The 30th anniversary edition will be mailed as soon as possible.

福 G.I.N.I. - GAZETTE INTERNATIONAL

福

Fifth International
**POLIO AND
INDEPENDENT
LIVING
CONFERENCE**
St. Louis, Missouri

INTERNATIONAL VENTILATOR USERS NETWORK

NETWORKING INSTITUTE 福 IPN - INTERNATIONAL

福 POLIO NETWORK - I.V.U.N.

Wednesday, May 31, 1989, 8:30 a.m.
through
Sunday, June 4, 1989, 12:00 noon

Organized and Sponsored by
Gazette International Networking Institute (G.I.N.I.)
International Polio Network (IPN)
International Ventilator Users Network (I.V.U.N.)
4502 Maryland Avenue, St. Louis, MO 63108 U.S.A.
314/361-0475

PROGRAM

This program is tentative and subject to change.

Tuesday, May 30, 1989

5:00 p.m. – 8:30 p.m. Registration

Wednesday, May 31, 1989

INDEPENDENT LIVING WORLDWIDE

7:30 a.m. – 5:30 p.m. Registration

7:30 a.m. – 8:30 a.m. Continental Breakfast

8:30 a.m. – 11:45 a.m.

"Impact of National Policy on Independent Living: International Case Studies"

Trevor Boyle, Phab (N.I.), Belfast, Ireland
Uwe Frehse, Munich, West Germany
Eileen Giron, ACOGIPRI, San Salvador, El Salvador
Judy Heumann, World Institute on Disability, Berkeley, CA
Rachel Hurst, London, England
Holger Kallehauge, High Court Judge, Denmark
Joshua T. Malinga, Disabled Peoples' International, Bulawayo, Zimbabwe
Derrick L. Palmer, Kingston, Jamaica
John L. Quigley, Jr., D.Min., G.I.N.I., St. Louis, MO
Adolph Ratzka, Ph.D., Royal Institute of Technology, Stockholm, Sweden
Robert J. Ronald, S.J., Operation De-Handicap, Taipei, Taiwan
Magdy Shams, Ph.D., Ain Shams University, Cairo, Egypt
Max Starkloff, Paraquad, St. Louis, MO
Zhang Li, Beijing Children's Welfare Institution, Beijing, China

1:30 p.m. – 4:45 p.m.

"What Really Limits Us? – Elevating Everyone's Expectations"

Speed Davis, MA Office of Handicapped Affairs, Boston, MA
Richard Goodwin, IMPACT, Inc., Alton, IL
Anne M. Isberg, Legal Advisor, Copenhagen, Denmark
Edward Roberts, World Institute on Disability, Berkeley, CA
Carol Rowse, Wellington, New Zealand
August Ruggeberg, Ph.D., Munich, West Germany
Max Starkloff, Paraquad, St. Louis, MO

Thursday, June 1, 1989

THE LATE EFFECTS OF POLIO

7:30 a.m. – 5:30 p.m. Registration

7:30 a.m. – 8:30 a.m. Continental Breakfast

8:30 a.m. – 11:45 a.m.

"International Progress Reports: Networking and Research"

James C. Agre, M.D., Ph.D., University of Wisconsin Hospitals and Clinics, Madison, WI
Ruth Bell, D.N.Sc., University of Maryland, Columbia, MD
Neil R. Cashman, M.D., Montreal Neurological Institute and Hospital, Montreal, Quebec, Canada
Carl A. Coelho, Ph.D., Gaylord Hospital, Wallingford, CT
Marinos Dalakas, M.D., National Institutes of Health, Bethesda, MD
Rubin M. Feldman, M.D., FRCP(C), University of Alberta Hospitals, Edmonton, Alberta, Canada

Michael Fillyaw, RPT, University of Vermont, Burlington, VT
D. Armin Fischer, M.D., Rancho Los Amigos Medical Center, Downey, CA
Joan Headley, M.S., International Polio Network, St. Louis, MO
Jong Seok Kim, Ph.D., Korea Polio Foundation, Seoul, Korea
Audrey King, M.A., Hugh MacMillan Medical Centre, Toronto, Ontario, Canada
Richard Owen, Sister Kenny Institute, Minneapolis, MN
Raymond Roos, M.D., University of Chicago, Chicago, IL
Roberta Simon, R.N., Darien, IL
Gertrud Weiss, Rosenheim, West Germany
Anthony J. Windebank, M.D., Mayo Clinic, Rochester, MN

1:30 p.m. – 4:45 p.m.

"Prescription for Fatigue, Underventilation, and Weakness"

James C. Agre, M.D., Ph.D., University of Wisconsin Hospitals and Clinics, Madison, WI
Neil R. Cashman, M.D., Montreal Neurological Institute and Hospital, Montreal, Quebec, Canada
Jane Dummer, Baltimore, MD
Frederick Maynard, M.D., University of Michigan Medical Center, Ann Arbor, MI
Jacquelin Perry, M.D., Rancho Los Amigos Medical Center, Downey, CA
Geoffrey T. Spencer, FFARCS, St. Thomas' Hospital, London, England
William Waring, M.D., University of Michigan Medical Center, Ann Arbor, MI
Martin B. Wice, M.D., St. John's Mercy Medical Center, St. Louis, MO

Friday, June 2, 1989

THE LATE EFFECTS OF POLIO

7:30 a.m. – 5:30 p.m. Registration

11:00 a.m. – 6:00 p.m.

Abilities Expo-Midwest at Cervantes Convention Center (Free admission)

7:30 a.m. – 8:30 a.m. Continental Breakfast

8:30 a.m. – 11:45 a.m.

"Prescription for Pain, Exercise, and Energy Conservation"

Thomas P. Anderson, M.D., Spaulding Rehabilitation Hospital, Boston, MA
Nancy Caverly, St. Louis, MO
Glenn Ham-Rosebrock, C.O., Downey, CA
Ernest W. Johnson, M.D., The Ohio State University, Columbus, OH
Frederick Maynard, M.D., University of Michigan Medical Center, Ann Arbor, MI
Jacquelin Perry, M.D., Rancho Los Amigos Medical Center, Downey, CA
Renah Shnaider, Oakland, California
Dorothy Woods Smith, Westbrook, Maine
Jennine Speier, M.D., Sister Kenny Institute, Minneapolis, MN

1:30 p.m. – 4:45 p.m.

"Psychological Adjustment: Several Points of View Including Yours"

Ruth Bell, D.N.Sc., University of Maryland, Columbia, MD
Michael A. D'Anton, Ph.D., Welkind Rehabilitation Hospital, Rockaway Borough, NJ
Lauro Halstead, M.D., National Rehabilitation Hospital, Washington, D.C.
Stanley Yarnell, M.D., St. Mary's Hospital and Medical Center, San Francisco, CA

PROGRAM *(continued)*

Saturday, June 3, 1989

7:30 a.m. – 5:30 p.m. Registration

11:00 a.m. – 6:00 p.m.

Abilities Expo-Midwest
at Cervantes Convention Center *(Free admission)*

7:30 a.m. – 8:30 a.m. Continental Breakfast

8:30 a.m. – 11:45 a.m.

ETHICAL CHALLENGES AND SOCIAL POLICY RELATED TO DISABILITY & AGING

Augusta Alba, M.D., Goldwater Memorial Hospital, New York, NY

Lawrence C. Becker, Ph.D., Hollins College, Roanoke, VA

Agatha Colbert, M.D., Lakeville Hospital, Lakeville, MA

Jack Genskow, Ph.D., Sangamon State University, Springfield, IL

Bente Madsen, Frederiksberg, Denmark

Frederick Maynard, M.D., University of Michigan Medical Center,
Ann Arbor, MI

Ingolf Osterwitz, Ph.D., Hildesheim, West Germany

August Rugeberg, Ph.D., Munich, West Germany

Daniel Wikler, Ph.D., Medical School, University of Wisconsin,
Madison, WI

Irving K. Zola, Ph.D., Brandeis University, Waltham, MA

1:30 a.m. – 5:30 p.m.

HOME MECHANICAL VENTILATION WORKSHOP

Augusta Alba, M.D., Goldwater Memorial Hospital, New York, NY

Carl A. Coelho, Ph.D., Gaylord Hospital, Wallingford, CT

Agatha Colbert, M.D., Lakeville Hospital, Lakeville, MA

Jerry Daniel, Vancouver, WA

Redento Ferranti, M.D., Gaylord Hospital, Wallingford, CT

Jack Genskow, Ph.D., Sangamon State University, Springfield, IL

Allen I. Goldberg, M.D., Chicago, IL

Joseph Kaufert, Ph.D., University of Manitoba, Winnipeg, Manitoba,
Canada

Gini Laurie, G.I.N.I., St. Louis, MO

Virginia Nelson, M.D., University of Michigan Medical Center,
Ann Arbor, MI

Oscar A. Schwartz, M.D., St. Mary's Health Center, St. Louis, MO

Susan Sortor, R.R.T., Dallas Rehabilitation Institute, Dallas, TX

Geoffrey T. Spencer, FFARCS, St. Thomas' Hospital, London, England

Sunday, June 4, 1989

SPECIAL INTEREST WORKSHOPS

(See reverse side of Registration Form)

7:30 a.m. – 8:30 a.m.

Registration and Continental Breakfast

11:00 a.m. – 5:00 p.m.

Abilities Expo-Midwest
at Cervantes Convention Center *(Free admission)*

7:30 a.m. – 8:30 a.m. Support Group Leaders'
Meeting

8:30 a.m. – 9:30 a.m. Session I

9:45 a.m. – 10:45 a.m. Session II

11:00 a.m. – 12:00 a.m. Session III

HOTEL

Space has been reserved at the SHERATON ST. LOUIS. See Hotel Reservation Form enclosed for rates and details (return this form to the SHERATON ST. LOUIS) or call FLYING WHEELS at 1-800-657-4446. Special requests for hotel accommodations should be made through International Polio Network or Flying Wheels.

EQUIPMENT

Individuals wanting to rent a battery charger, 3-wheeler, motorized wheelchair, or hydraulic lift, should make arrangements with HOME HEALTH CARE EQUIPMENT SERVICES, INC., Mr. Joe Neels, 7790 Watson Road, St. Louis, MO 63119. 314/968-1616.

VENTILATORS

Individuals needing to rent a rocking bed, iron lung, or other ventilatory equipment, should make arrangements, 30 days in advance, with LIFECARE, Mr. Jack Craigs, 408 NW Business Park Lane, Riverside, MO 64150. 816/741-7667.

TRANSPORTATION

Domestic Flights To receive the special rates offered by TRANS WORLD AIRLINES (TWA), the official conference carrier, call the following toll-free numbers between 7:15 a.m. and 7:00 p.m. (CT): In the United States 1-800-325-4933 or call FLYING WHEELS at 1-800-657-4446. In either case, refer to "profile number" 9914194.

International Flights Registrants arriving on international flights must contact FLYING WHEELS TRAVEL, P.O. Box 382, Owatonna, MN 55060, 1-507-451-5005, in order to qualify for special rates offered by TRANS WORLD AIRLINES (TWA), the official conference carrier.

Airport to SHERATON ST. LOUIS AIRPORT LIMOUSINE van service runs every 20 minutes to downtown St. Louis. This service does not accommodate individuals requiring a lift van (see below). The desk is on the lower level of Lambert International opposite Baggage Carousel #4 and next to Exit 13. Tickets are \$6 one way and \$11 round trip. 1-314-429-4940.

Individuals requiring a lift van must contact FLYING WHEELS TRAVEL, P.O. Box 382, Owatonna, MN 55060, (1-800-657-4446). This service is being provided by the ST. LOUIS SOCIETY FOR CRIPPLED CHILDREN. The fee is \$20/person round trip.

Taxicabs are waiting outside Exit 7. County Cab Co. 991-5300. Yellow Cabs 991-1200. The fare one way is \$16-\$18.

PARKING

If you are the registered guest of the Sheraton St. Louis, you can park in the lot adjacent to the hotel at a charge of \$7.00 per day. You may leave and return at any time without additional charges. If you have other accommodations and wish to park on that lot, you will have to pay the hourly rates posted at the entrance.

FRIDAY NIGHT IN ST. LOUIS

Friday evening (June 2) dinner will not be included in the meal package. For advanced information about the city of St. Louis, scheduled events, accessible restaurants, etc., contact St. Louis Convention & Visitors Commission Tourism Information: 1-800-247-9791. For the brochure "Access St. Louis," contact Office on the Disabled, City Hall, Room 30, St. Louis, MO 63103 or call 314/622-3686.

The St. Louis Cardinals will be playing a night game with the Chicago Cubs. The game starts at 7:35 p.m. If you wish to charge tickets on Visa or MasterCard, call 314/421-2400 after March 13, 1989 or write to: St. Louis Cardinals, Ticket Office, P.O. Box 8787, St. Louis, MO 63102 (checks accepted).

Fifth International Polio and Independent Living Conference

REGISTRATION FORM

May 31 – June 4, 1989 ■ Sheraton St. Louis Hotel

DEADLINE: MAY 1, 1989

Mail to:
G.I.N.I.
4502 Maryland Avenue
St. Louis, MO 63108

PERSONAL INFORMATION

Date _____

Name _____

Home Address _____

City _____ State _____ Zip _____ Country _____

Institution _____

Title _____

Business Address _____

City _____ State _____ Zip _____ Country _____

Home Phone _____ Business Phone _____

REGISTRATION*

Full Registration

	Prior to April 1	After April 1
Individual with Disability	<input type="checkbox"/> \$80	<input type="checkbox"/> \$100
Individual with Disability and Attendent/Family	<input type="checkbox"/> \$135	<input type="checkbox"/> \$155
Health & Rehabilitation Professionals	<input type="checkbox"/> \$200	<input type="checkbox"/> \$220

Single Day Registration

Individual with Disability		
<input type="checkbox"/> Wed <input type="checkbox"/> Thurs <input type="checkbox"/> Fri <input type="checkbox"/> Sat <input type="checkbox"/> Sun	(\$20/day) \$ _____	(\$30/day) \$ _____
Individual with Disability and Attendent/Family		
<input type="checkbox"/> Wed <input type="checkbox"/> Thurs <input type="checkbox"/> Fri <input type="checkbox"/> Sat <input type="checkbox"/> Sun	(\$35/day) \$ _____	(\$45/day) \$ _____
Health & Rehabilitation Professional		
<input type="checkbox"/> Wed <input type="checkbox"/> Thurs <input type="checkbox"/> Fri <input type="checkbox"/> Sat <input type="checkbox"/> Sun	(\$50/day) \$ _____	(\$60/day) \$ _____

*Registration includes a served Continental breakfast each day.
NOTE: In the event of cancellation, we will be able to refund 85% of the registration fee if cancellation is made prior to May 15, 1989. Registration fee will not be refunded after May 15, 1989.

Registration subtotal \$ _____

MEALS

Reservations for complete package for _____ persons at \$115 per person (including tips and taxes). Fee includes lunch on Wed., Thurs., Fri., Sat. & dinner on Wed., Thurs., and Sat. (There is no dinner planned for Friday evening. Continental breakfasts are included in registration fee.).

Reservations for Individual Meals:

<input type="checkbox"/> Wed. lunch \$14.00	<input type="checkbox"/> Thurs. lunch \$14.00	<input type="checkbox"/> Fri. lunch \$14.00	
<input type="checkbox"/> Wed. dinner \$19.00	<input type="checkbox"/> Thurs. dinner \$19.00	<input type="checkbox"/> Sat. lunch \$14.00	
		<input type="checkbox"/> Sat. banquet \$25.00	Meals subtotal \$ _____

(If you have any dietary restrictions, please notify G.I.N.I., 4502 Maryland Avenue, St. Louis, MO 63108.)

PAYMENT OF FEES

Please indicate method of payment:

<input type="checkbox"/> Check or Money Order (U.S. dollars only; payable to G.I.N.I.)	Registration subtotal \$ _____
<input type="checkbox"/> MasterCard <input type="checkbox"/> Visa Card No. _____	Meals subtotal \$ _____
Expiration date _____ Signature _____	Total \$ _____

FOR OFFICE USE ONLY		
CR	PD	RD



Call us with your travel plans to the Conference!!!

We will make your reservations for:

- AIRLINE TRANSPORTATION
- HOTEL ACCOMMODATIONS AT THE SHERATON
- AND WHEELCHAIR VAN TRANSFERS FROM THE AIRPORT

One Toll Free Call to FLYING WHEELS Does It All!

AIRLINE TRANSPORTATION — TWA has been selected as the official domestic and international airline carrier to the Conference. As the official travel agency, FLYING WHEELS will be able to offer you a discount on your airline ticket for travel on TWA.

If your home city is not serviced by TWA, or you prefer a different schedule, FLYING WHEELS will advise you of other airline carrier fares and schedules.

Please be assured that we will offer you the lowest fare applicable for your desired dates of travel. Airline fares do vary greatly and we have the most sophisticated airline computer to give you up-to-date fares and schedules. Check with us today!

HOTEL ACCOMMODATIONS — The Sheraton St. Louis will be the site of the Polio Conference. When you call us, we will be able to make your hotel reservation for your desired number of nights . . . and take care of your special requests.

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We will be coordinating all passenger arrivals and departures for wheelchair van service in St. Louis.

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Please detach and return to: Sheraton St. Louis Hotel, 910 N. Seventh Street, St. Louis, MO 63101.
Make checks payable to: Sheraton St. Louis Hotel

Name(s) _____

Sharing with _____

Address _____ Residential Business

City _____ State _____ Zip _____ Country _____

Phone Numbers (Residential) _____ (Business) _____

Arrival Date _____ Arrival Time _____ Departure Date _____

No. of Rooms _____ No. of Persons _____

Circle preferred rates:

May 31 through June 4, 1989

Single \$70.00

Double: \$70.00

Triple: \$85.00

Quad: \$100.00

RETURN TO THE SHERATON ST. LOUIS HOTEL BY APRIL 30, 1989

If rate requested is not available, next available rate will apply.

Reservations received after specified date will be accommodated on a rate and space availability basis only.

Check-out time is 1:00 p.m. Normal Check-in time is after 3:00 p.m.

Reservations are held until 4:00 p.m. unless guaranteed by a one night's deposit or guaranteed with one of the following credit cards: American Express, Diners Club, Carte Blanche, Visa, MasterCard or En Route.

Credit Card _____ Exp. Date _____ Type _____

HOTEL PHONE: 314/231-5100



The Sheraton St. Louis Hotel

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SPECIAL INTEREST WORKSHOPS

SUNDAY, JUNE 4, 1989

Attendees will be able to participate in three one-hour workshops on Sunday morning. To facilitate scheduling, each registrant should select three workshops that are of the most interest and return to G.I.N.I. along with the registration form.

FOR MEN ONLY

The content of this workshop will be determined by the participants. Suggestions of specific topics should be sent to Jack Genskow, Ph.D., 1916 Claremont, Springfield, IL 62703.

FOR WOMEN ONLY

The content of this workshop will be determined by the participants. Suggestions of specific topics should be sent to Nancy Caverly, 389 North Mosley Road, St. Louis, MO 63141.

COMPUTER ADAPTATIONS

Discussion and presentation of computer-related adaptive devices and software.

FINANCIAL PLANNING TO PRESERVE ENTITLEMENTS

Financial and legal advice for persons with disabilities and their families to avoid losing government benefits.

LEGAL RIGHTS AND LEGAL ISSUES

A panel presentation on legal rights and issues affecting individuals with disabilities such as the right to an education, airline travel, etc.

THE SUPPORT GROUP LEADER'S ROLE AS A PEER COUNSELOR

Techniques and strategies for helping peers cope with familiar problems.

RECREATIONAL ADAPTATIONS

Discussion and presentation of adaptive devices for recreational use.

LIVING ALONE

How one individual with a significant disability manages to live a "normal" life.

REACHING MINORITIES

Report and discussion concerning attitudes of minority individuals and the self-help movement.

REHABILITATION ENGINEERING

An opportunity to share environmental adaptive techniques and to suggest innovative devices.

COPING WITH DISABILITY AND AGING

Similarities and differences between individuals who have aged with their disability and those who are dealing with a new disability in later life.

ARCHITECTURAL BARRIERS AND DISABILITY

The importance of accessibility as a requisite for independent living.

VOLUNTEER SERVICE BANK

Description of a unique program in which volunteers earn credit hours for assisting persons with disabilities.

CURRENT THESIS REPORTS ON THE LATE EFFECTS OF POLIO

Doctoral and master's level candidates will present their findings. Qualified individuals interested in presenting should contact Joan Headley, 4502 Maryland Avenue, St. Louis, MO 63108.

AD HOC PRESENTATIONS

A potpourri of topics. Individuals interested in presenting should contact Joan Headley, 4502 Maryland Avenue, St. Louis, MO 63108.

STATISTICAL INFORMATION

Please complete the following information for each person attending the Conference. This information will be used to help us serve your needs at the Conference and for statistical purposes. All information will be confidential.

Country of residence _____ State or province _____

Sex: Male Female Age _____ How many G.I.N.I. Conferences have you attended? _____

Disability: Polio Late Effects of Polio Spinal Cord Injury Muscular Dystrophy
 Multiple Sclerosis ALS Other _____

Equipment: Braces Cane Crutches Manual Wheelchair Motorized Wheelchair
 Three-Wheeler Other _____

Ventilator: Type _____ Average hours of use _____ Bringing own equipment Renting

Mode of transportation to Conference: Air Motor Vehicle Train

Arrival Date and Time _____ Departure Date and Time _____

Number of Attendants _____ Do you belong to a support group? Yes No

Will you require a Brailled program? Yes No Will you require a sign language interpreter? Yes No

You are cordially invited to attend and to help with the expenses of the*



May 31-June 4, 1989, Sheraton St. Louis Hotel

Wednesday, May 31.

- **Independent Living Worldwide.**

Thursday and Friday, June 1-2.

- **Late Effects of Polio: Research, Symptoms, and Management.**
- **Late Effects of Polio: Psychological Adjustment.**

Saturday, June 3.

- **Ethical Challenges and Social Policies of Disability and Aging.**
- **Home Mechanical Ventilation Workshop.**

Sunday, June 4.

- **Special Interest Workshops.**

Friday - Sunday, June 2-4.

- **Abilities Expo-Midwest at the Cervantes Convention Center.**

* This conference is partially funded, once again, by the goodwill of the presenters who are paying their own expenses. Your "Brown Bag" contribution will supplement the expenses of some participants with disabilities from around the world.

Here is my "Brown Bag" contribution (Donations are tax-deductible):

Name _____

Address _____

Amount enclosed \$ _____ Make checks payable to: G.I.N.I. (Memo: Brown Bag)

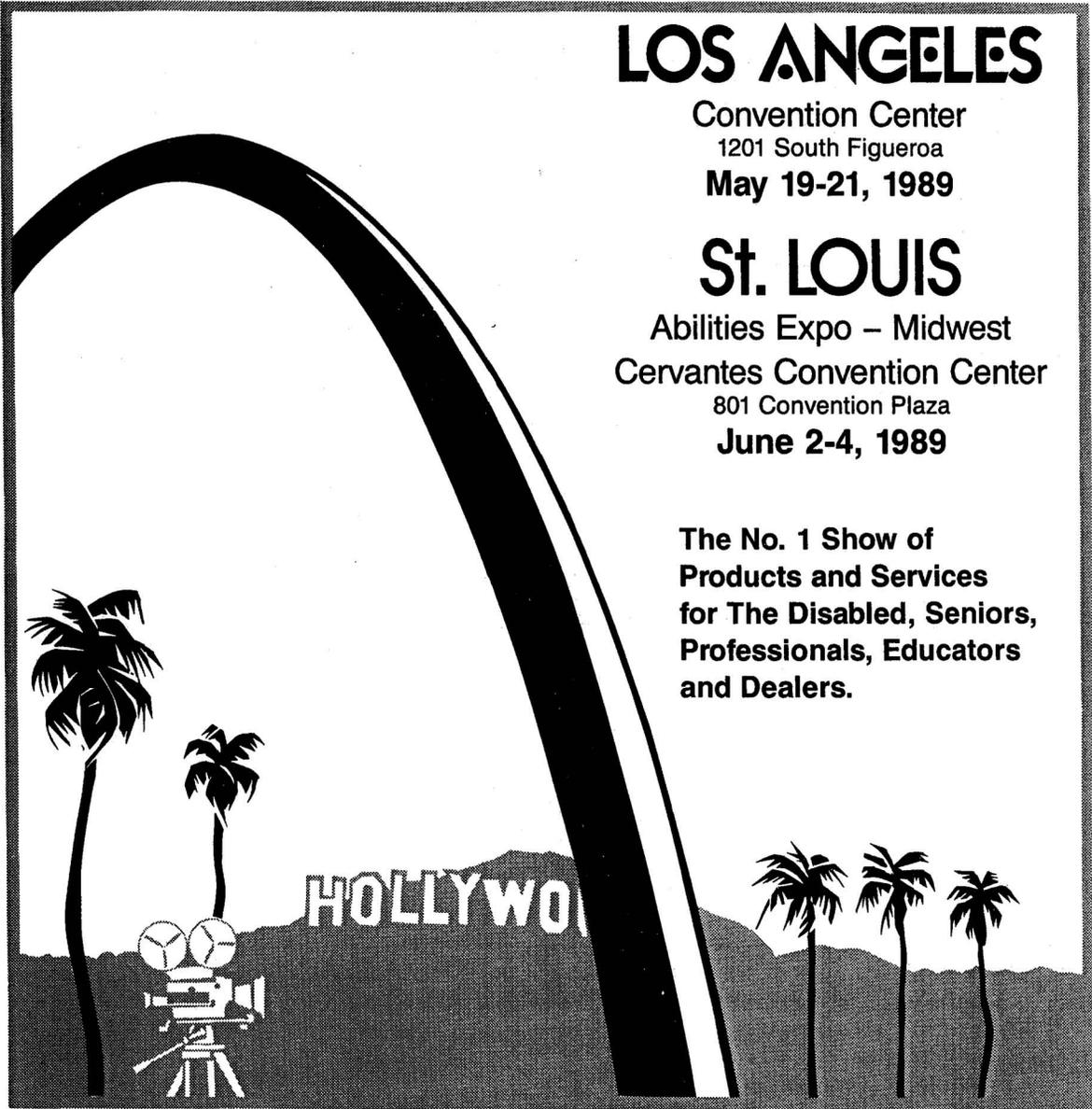
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Information on...

Insurance Concerns

International Polio Network has received letters of concern about the wide-spread advertising of the late effects of polio and the ability to obtain insurance. Polio survivor Jack Hannaford, Second Vice-President and Associate Actuary, General American Life Insurance Company, St. Louis, checked with medical directors, underwriting management, and actuaries in the industry and found no evidence to substantiate this fear.

Representatives from Mutual of Omaha, Travelers, and Lincoln National all report "nothing special is being done" that might exclude the polio survivor. Applicants for insurance are being underwritten only on the basis of their current physical condition.

If you are having problems (or have had problems) with a company, obtain the rejection in writing and contact International Polio Network so we can see if an unfavorable trend might be developing.

Policy Bulletin on Insurance

The World Institute on Disability has published its first of three policy bulletins on the financing of health care for persons with severe chronic conditions.

"Measuring the Health Insurance Needs of Persons with Disabilities and Persons with Chronic Illness" is a comprehensive 64-page booklet which defines and measures the health care needs of the target population, explores the evolution and limitations of private and public health insurance, and analyzes federal and state policy options for more equitable health care financing for persons with disabilities or chronic illness.

Contact World Institute on Disability (WID), 1720 Oregon Street, Suite 4, Berkeley, CA 94703

(415/486-8314) for a copy of the first bulletin (\$3). WID received a one-year grant from the National Institute on Disability and Rehabilitation Research (NIDRR) to publish this series.

Job Accommodation Network: JAN

The Job Accommodation Network (JAN) provides information which greatly enhances the ability of employers to provide reasonable and appropriate job accommodations for qualified persons with disabilities and increases job opportunities for persons with disabilities.

This network maintains a database which catalogues and stores information on job accommodations that have been successfully used in the workplace by other employers. The database also contains other information concerning job accommodations, such as resources including the names and addresses of individuals and organizations experienced in the modification of work environments for persons with disabilities.

To the uninitiated, job accommodations appear so expensive that they discourage some employers from implementing them. This would typically be translated into a lost employment opportunity for the person and the employer as well. However, cost is not the major factor in most job accommodation decisions. This view is supported by a study performed by the U.S. Department of Labor (1982).

The lack of employer awareness concerning job accommodations hampers the employment of individuals with disabilities more than the expense that might be involved. Unfortunately, few employers have adequate information concerning the employability of individuals with a disability and of job accommodation techniques.

JAN is the central resource to which an employer can turn for information on relevant options. Access to the Job Accommodation Network is through a toll free number: 1-800-JAN-PCEH. Information is then retrieved and transmitted by individuals who are skilled in translating the employer's expressed needs into specific, targeted job accommodation strategies or techniques. Employers using the network also have access to other information resources such as the National Rehabilitation Information Center, ABLEDATA, Lockheed Dialogue, and a network of experts who serve as resource consultants in cases involving unusual or difficult accommodation problems.

Social Security

Polio Network News has not reported on Social Security issues since July of 1987 when it published the SSA Program Circular, Late Effects of Anterior Poliomyelitis (Polio).

At that time, the Office of Disability of the Social Security Administration issued guidelines on poliomyelitis to personnel who interview, adjudicate, or review disability claims. Interested persons can find this 3-page guide, "Evaluation of the Late Effects of Poliomyelitis," at their local social security offices. Ask for Program Operations Manual Systems (POMS), Part 04, Section DI 24580.010.

On May 24, 1988, the Office of Disability mailed to all its Regional Offices a video presentation discussing the late effects of polio. (Your local district office can put you in touch with the regional office.) The tape by Dr. Neal Cashman, now at the Montreal Neurological Institute, was sent on an informational basis and is available to personnel who adjudicate and/or review disability claims.

For a copy of an updated version of "What You Should Know About Your Social Security Case," send \$2 to IPN, 4502 Maryland Avenue, St. Louis, MO 63108. Also, there is a national organization of lawyers who specialize in social security disability cases. The National Organization of Social Security Claimant Representatives (NOSSCR) can provide names of lawyers who are members anywhere in the United States. Call 1-800-431-2804.

POTPOURRI

Support Leader Requests

The Polio Connection, which is the greater Cincinnati support group, is seeking help from leaders throughout the network to answer the following question. "What methods have groups used to compile physician registries?" Send your experiences and suggestions to Sylvia Meek, 6576 Devonwood Drive, Cincinnati, OH 45224.

Kay LaGrone, from Austin, TX, has a similar question. "What approach have groups used to help doctors who are not familiar with the late effects of polio better understand the problems now facing polio survivors?" Send your comments and suggestions to Kay LaGrone, 6907 Fireoak Drive, Austin, TX 78759.

David Kelly, Lake Tahoe Polio Network, would like groups to send him examples of their newsletter prior to the Fifth International Polio and Independent Living Conference May 31-June 4, 1989 in St. Louis. Also, if you have physical problems operating Nintendo, contact David Kelly, P.O. Box 10005, South Lake Tahoe, CA 95731.

Texas Polio Survivors' Association (TPSA) will publish a cookbook as part of their fundraising activities for 1989. To submit recipes, contact DeValca White, TPSA, P.O. Box 35688, Houston, TX 77235-5688.

POTPOURRI

Update on Anthology

Sunny Roller and Charlene Bozarth of Michigan wish to thank everyone who submitted manuscripts for inclusion in their anthology of creative writings by polio survivors. Due to the large number of entries, more time is needed to review the material. If your manuscript is to be included, you will be notified no later than December 31, 1989. Questions and comments should be sent to Charlene Bozarth, 4815 Arapaho, Okemos, MI 48864.

Fellowship Applications

The International Disability Exchanges and Studies Project administered by World Institute on Disability (WID) and Rehabilitation International is accepting applications for 1989 fellowships. The project's purpose is to fund U.S. disability specialists, researchers, and research institutions to study exemplary programs abroad. The deadline for applications is June 1, 1989. For more information contact WID, 1720 Oregon Street, Suite 4, Berkeley, CA 94703. 415/486-8314. Disabled individuals are encouraged to apply.

World Health Day

The April 7, 1989 theme, "Health For All: Pass It Along" reflects the importance of communication at all levels in the promotion of health through both personal and collective responsibility. The ultimate goal is to have as many people as possible in the U.S. and the World communicating about health. The event provides each person with the opportunity to examine his or her lifestyle practices and to gain a better understanding of health conditions throughout the world.

For more information and a complete World Health Day 1989 planning kit, please write: American Association

for World Health, 2001 "S" Street, N.W., Suite 530, Washington, D.C. 20009 or call 202/265-0286.

ABLEDATA

The Adaptive Equipment Center at Newington Children's Hospital, Newington, CT will now manage a computerized database, called ABLEDATA, which contains more than 15,000 commercially-available products from 1,800 manufacturers.

Information from ABLEDATA can be obtained by calling a nation-wide toll-free number, 1-800-344-5405 (accessible by voice and TDD) during normal business hours (in CT, call 667-5405) or by writing The Adaptive Equipment Center, Newington Children's Hospital, 181 East Cedar Street, Newington, CT 06111. ABLEDATA is also accessible to computer users. Contact BRS Information Technologies directly by calling 1-800-345-4BRS.

Padded Leg Belt

For details about a secure padded leg belt (\$16.95 + P/H), contact DVA Helps, 1425 East 22nd Avenue, North Kansas City, MO 64116. 816/221-0674.

PUBLICATIONS

Stress-Management Book

For more information about a 145-page book, Quicki-Mini Stress-Management Strategies for You, A Person with a Disability, contact David G. Danskin, Guild Hall Publications, P.O. Box 133, Manhattan, KS 66502-0002. Tape and Braille versions are available at the same price of \$12.50 plus \$2.50. (Bulk rates are also available.)

Home Health Aides

For more information about a 352-page book, Home Health Aides: How to Manage the People Who Help You,

contact Aldred H. DeGraff, Saratoga Access Publications, Box 2346, Clifton Park, NY 12065. Single copies are \$18.95 + \$2 P/H; multiple-copy discounts are available to independent living programs and agencies.

Air Travel for Wheelchair Users
Free copies of "Ten Questions and Answers About Air Travel for Wheelchair Users," can be obtained by writing to the Eastern Paralyzed Veterans Association, 75-20 Astoria Blvd., Jackson Heights, NY 11370-1178 or by calling 718/803-EPVA.

Products to Assist the Sportsman
To request the catalog, Products to Assist The disabled Sportsman, write J.L. Pachner, LTD., P.O. Box 164, Trabuco Canyon, CA 92678.

IPN Membership Renewal Notices

In January, IPN mailed renewal notices to individuals whose memberships are due this quarter. Please renew by returning the card with a check for \$8.00 so you will receive the Spring Polio Network News (Vol. 5, No. 2). (Membership in G.I.N.I. does not include the Polio Network News.)

Post-Polio Directory 1989

The Post-Polio Directory - 1989 listing clinics, support groups, and health professionals is now available from IPN. This new edition includes an international section. All paid members of International Polio Network receive the directory.

Your Help Is Needed!!

To ensure the NATIONAL POLIO AWARENESS WEEK proclamation, individual polio survivors and support groups in each state must request their Senators and Congressmen to co-sponsor the proclamation.

International Polio Network also suggests that support groups request their governors to issue statewide proclamations for the same week. When this event occurs, we encourage you to notify IPN and to submit any photographs, news clippings or any other documentation for inclusion in the Spring Polio Network News.

The AMERICANS WITH DISABILITIES ACT (ADA) will be re-introduced in the 101st Congress although no date has been set.

This landmark bill is designed to eliminate discrimination against persons with disabilities. No person shall be subjected to discrimination on the basis of handicap in these basic areas.

Employment practices covered by The Civil Rights Act.

Housing sale and rental of housing covered by the Fair Housing Act.

Transportation Services.

Public Accommodations and Services.

Communications.

The Act will not repeal Sections 503 (employment) and 504 (facilities receiving federal money) of the Rehabilitation Act of 1973.

If you are concerned about the rights of persons with disabilities, contact your legislators and urge them to co-sponsor the ADA.

International Polio Network

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Calendar

March 18, 1989. Post-Polio Conference. Tri-Cities, WA.
Contact: Julia Smith, 2404 Blvd., Richland, WA 99352.
509/943-2563.

April 1, 1989. Polio Update '89. Red Lion Inn, Omaha, NE.
Contact: Nancy Carter, P.O. Box 37139, Omaha, NE 68137.
402/895-2475.

April 6, 1989. The Late Effects of Polio. Embassy Suite Hotel, 220 West 43rd Street, Kansas City, MO 64111.
Contact: Sheryl Max, R.N., Research Medical Center, 2316 East Meyer Boulevard, Kansas City, MO 64132. 816/276-4118.

April 29-30, 1989. Texas-Oklahoma Post-Polio Symposium. Wichita Falls Hilton, 401 Broad, Wichita Falls, TX 76301.
Contact: Barbara Miller, 4503 Allison, Wichita Falls, TX 76308. 817/691-3497.

April 29, 1989. Post-Polio Conference. Oakbrook Marriott, Oakbrook, IL. Contact: Roberta Simon, R.N., 7835 Pine Parkway, Darien, IL 60559. 319/969-0287.

May 31-June 4, 1989. 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.

June 21-23, 1989. 4th Canadian Congress of Rehabilitation, Workers and Workplaces: Challenges and Innovations. Constellation Hotel, Etobicoke, Toronto, Canada. Contact: CRCDC Congress Secretariat, Suite 2110, One Yonge Street, Toronto, Ontario M5E 1E5. 416/862-0340.

October 4, 1989. Post-Polio Sequelae Conference. Allentown, PA. Contact: Beverly Solomon, Ph.D., 2200 Industrial Drive, Bethlehem, PA 18017-2198. 215/866-8092.

November 3-6, 1989. Managing Post Polio Problems. Delta Airport Inn, Delta, British Columbia. Contact: Rheta Davidson, 1701 Cedar Hill Cross Road, Suite 402, Victoria, British Columbia V8P 2P9. 604/477-6546.