

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.
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Spring 1989 ■ Vol. 5, No. 2

Questions and Answers

QUESTION: "Who establishes the post-polio clinics in the States and how are they organized?"

Henri Charcosset, Villeurbanne, France

ANSWER: To establish a post-polio clinic, a need has to be perceived for such a clinic. This perceived need may be generated by the medical community, but more likely the catalyst will come from the demands of the post-polio population, in particular, the support groups. A post-polio clinic can be organized if the appropriate expertise exists in the community. The best resource is a rehabilitation center which has a full complement of professionals able to meet the various aspects of the post-polio survivors' special needs in a coordinated fashion.

These professionals should be led by a physician specially trained to meet the needs of individuals with physical disabilities. A physiatrist whose formal training is a residency program in physical medicine and rehabilitation is best qualified. There are some cases of other physicians who also have developed a special interest and expertise in helping individuals with disabilities.

The multidisciplinary treatment team should also include a physical therapist, occupational therapist, speech therapist, recreational therapist, rehabilitation psychologist, rehabilitation social worker, rehabilitation nurse, a dietitian, orthotist (brace fabricator), and a vocational counselor. There should be access to specialists in pulmonary medicine, neurology, and orthopedic surgery.

One person in the rehabilitation center should be designated to coordinate the clinic program. His or her responsibility is to assemble the many medical professionals described above who will dedicate part of their practice to the post-polio clinic. The selected personnel will need to develop the special expertise to evaluate and treat individuals with post-polio

(continued on next page)

Questions and Answers

(Continued from page 1)

syndrome by examining the literature, attending seminars and conferences, or by visiting an established post-polio clinic.

(Consult the Post-Polio Directory or call International Polio Network.) The team members will need to be well versed in treatment techniques utilized in the past as well as newer protocols for the polio survivor.

Preliminary planning meetings of all disciplines are essential to (1) define roles, (2) establish goals, (3) determine treatment approaches, and (4) evaluate outcomes.

In our post-polio clinic at St. John's Mercy Medical Center in St. Louis, the client completes a medical history information sheet prior to the initial evaluation. The client is then seen by a physician who will review the client's medical history and perform a thorough neurologic and musculoskeletal examination. When appropriate, further evaluations by the treatment team will be arranged.

One member of the treatment team, a physical therapist (P.T.), measures range of motion, strength, and assesses mobility status. Based on the outcome of this evaluation, an individualized treatment is established to maintain or increase strength, to improve range of motion, to relieve pain, and to maximize mobility skills. An assessment may also be made to determine the need for ambulatory aids.

An occupational therapist (O.T.) evaluates daily living skills including an assessment of self-care and home management capabilities. This treatment may include instruction in energy conservation techniques and work simplification as well as suggestions for adaptive techniques and equipment to maximize the individ-

ual's participation in home and work activities.

A speech therapist assesses any speech or swallowing difficulties, and therapy is developed to maximize communication and safe swallowing skills.

A clinical rehabilitation psychologist provides individual and family counseling. The primary focus of counseling is to identify coping styles and to assist in learning to adjust to necessary lifestyle changes. Nutritional counseling is provided to assist persons requiring therapeutic or weight-reduction diets.

A recreational therapist assists clients in maximizing their recreational and leisure skills.

A rehabilitation nurse makes home visits and offers suggestions to make a client's home as accessible and functional as possible.

A rehabilitation social worker informs clients of the community resources available to them. When appropriate, the state department of vocational rehabilitation (VR) is contacted to provide vocational counseling including work evaluation. VR can facilitate appropriate job training to assist a client to return to his or her former job, even if adaptive equipment is necessary. Alternate job training and placement also may be arranged.

An orthotist works with the rehabilitation physician and the therapists to repair or modify older orthoses. In addition, the orthotist may fabricate new custom upper extremity, lower extremity, or spinal orthoses often using the latest light-weight plastics to maximize function, attractiveness, and comfort.

After the client has been through the appropriate evaluation and treatment program, the clinic staff will collaborate to ensure that all

of the special needs of the client have been addressed. If not, the coordinated treatment program will be modified. The client will usually return for a follow-up physician appointment in one to two months to assess the success of the program and to make sure the client's perceived needs and the needs perceived by the professional staff has been met. If needed, further evaluation and treatment is then prescribed.

The initial evaluation is done on a Monday so individuals traveling long distances have the opportunity to travel over the weekend. We do arrange for overnight stays at a minimal cost. With an out-of-town client an attempt is made to do the entire evaluation in one or two days with rest periods provided. The majority of our clients are within driving distance of our medical center so we set up the various professional appointments over several days to minimize fatigue.

We encourage our clients to join their local post-polio support group as peer interaction and support is an important complement to our program. We also encourage our clinic personnel to give lectures and to lead discussions at support group meetings in the surrounding area. The education of the client is a key part of our clinic. Handouts have been developed explaining work simplification, energy conservation, and home exercise programs and describing durable medical equipment options with sources of supply. Other appropriate handouts to meet any special need of the client are also available. We provide the Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors both to the client and, if appropriate, to his/her primary care physician.

Reimbursement for services is a billable item to the insurance companies within the guidelines of the client's policy. The ever-changing

climate in Medicare, Medicaid, and various insurers continues to be a challenge for the consumer, physician, therapist, and the hospital. In order to receive the entitled benefits, consumers should be very familiar with their coverage.

Our clients have found that our clinic has given them an avenue to express their fears and frustrations and the means to address their special physical, psychological, and social needs. The clinic personnel have found the sharing of their expertise a rewarding experience.

Post-polio clinic personnel of St. John's Mercy Medical Center, St. Louis, MO

QUESTION: "What Methods Have Groups Used to Compile Physician Registries?"

Sylvia Meek, Cincinnati, OH

ANSWER: The first step in locating knowledgeable physicians to work with your group is to poll your group. You may find that some of your members have a physician who is managing their difficulties quite well and is very knowledgeable.

The next step is to locate all the physiatrists and neurologists in your area that have experience in dealing with neuromuscular disorders. Contact your area hospitals and ask if they have staff physicians with these skills. Then contact the physicians and discuss with them the post-polio problem and the needs of your group.

If you are financially able, send them International Polio Network's (IPN) Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors to read. You may also refer them to other physicians in the country who are seeing polio survivors or have published medical

(continued on next page)

Questions and Answers

(Continued from page 3)

information. It is not necessary or advisable to send a lot of information as most physicians will not take hours of their time to peruse stacks of information.

I have made it a practice to screen physicians carefully and to be certain that they have seen several people with positive results before placing them on a referral list. You must constantly keep in mind that not everyone will be pleased with all physicians on your list because of personality conflicts or diagnosis and treatment concepts. One displeased client doesn't mean that the physician is not capable of caring for other people in a very satisfactory manner.

Expand your search to orthopods. You may find an orthopedic specialist that has an understanding of neuromuscular disorders. Some orthopods practicing today cared for polio survivors during the 1940s and 50s.

Finding a pulmonologist with knowledge of neuromuscular disorder may be a little more difficult. Underventilation and sleep difficulties relating to polio are poorly understood by many pulmonologists. Lungs are not the problem with most polio survivors but rather the muscles that make the lungs function. Collect literature that has been published by physicians working with IPN and provide that to the pulmonologist. Suggest that they telephone or write these physicians if they have any questions. Physicians in the Network are noted for their willingness to share.

Much has been published about the late effects of polio in medical journals, and almost every physician has seen some information somewhere. Physicians, also, are avid readers and attend many conferences and meetings. Do not enter these physicians' offices or

telephone them with the idea or attitude that you are better informed than they. It's an immediate turn off. Even though you may feel you are more knowledgeable, he/she is the licensed professional, and you are the potential client! (If possible, have a person in your group with a medical background approach doctors as one professional to another.)

Remember, all physicians see their role as helping patients, not hurting them. They want to assist you in any way possible. Be aware of their needs and feelings as well as your own!

Roberta Simon, R.N.,
Darien Park, IL

QUESTION: "What approach have groups used to help doctors who are not familiar with late effects of polio better understand the problems now facing polio survivors?"

Kay LaGrone, Austin, TX

ANSWER: Educating medical caregivers has been one of the primary goals of the New Mexico Polio Survivors Organization organized by my husband, Frank, and me less than a year ago.

Prior experience in Arizona had shown that many polio survivors attend one day conferences, but most physicians will not. One solution to this problem was offered by my general physician, Dr. Baker. He suggested that the guest speaker for our polio survivors' quarterly meeting speak at the weekly CME meeting (Continuing Medical Education) held at the local hospital. That way, he reasoned, we would be guaranteed a "captured" audience.

We invited Dr. Stanley Yarnell, San Francisco, to speak at our hospital in Las Cruces. It worked! He addressed one of the largest gatherings at our hospital for a CME meeting, physicians at Beaumont

Hospital in El Paso, and our regular quarterly survivors' meeting on the third day.

It worked, we believe, because physicians did not have to change their regular schedule, and they were more relaxed in their own environment and more likely to ask questions. With only physicians in attendance, no one is worried about whether or not a patient hears him/her ask a question. You may agree or disagree with separate meetings for physicians and consumers, but many physicians were educated.

We did not use our own funds for our guest speakers simply because we have no funds in New Mexico. Please contact me for a few ideas on how to raise funds.

Caroleanne Green
1008 Ivydale Drive
Las Cruces, New Mexico 88005.

Post-Polio Bibliography

"Abdominal Distention As An Indication of Post-polio Ventilatory Insufficiency" (Clinical note) by R.J. Saltzstein, et al. American Journal of Physical Medicine & Rehabilitation, April 1988, Vol. 67, No. 2. Pages 85-6.

"The Late Effects of Poliomyelitis" by L.W. Epperson. Alabama Journal of Medical Science, April 1988, Vol. 25, No. 2. Pages 173-7.

"Post-Polio Syndrome" by J.S. Shepard. Indiana Medicine, May 1988, Vol. 81, No. 5. Pages 428-30.

"Motor Neuron Disease & Past Poliomyelitis in England & Wales" by C.N. Martyn, et al. Lancet, June 1988, Vol. 11, No. 1(8598). Pages 1319-22.

"Dysphagia in Postpolio Sequelae: Report of Three Cases" C.A.

Coelho, et al. Archives of Physical Medicine & Rehabilitation, August 1988, Vol. 69, No. 8. Pages 634-6.

"The Postpolio Syndrome. An Overuse Phenomenon" by J. Perry, et al. Clinical Orthopaedics, August 1988, No. 233. Pages 145-62.

"Post-poliomyelitic Motor Neuron Disease. Clinical Aspects & Its Relation to Typical Motor Neuron Disease" by P. Meineir, et al. European Neurology, 1988, Vol. 28, No. 4. Pages 177-80.

"Occupational Therapy and the Post-polio Syndrome" by Grace R. Young. American Journal of Occupational Therapy, February 1989, Vol. 43, No. 2. Pages 97-103.

Post-Polio Research

In 1986, Sister Kenny Institute, Minneapolis, MN, was awarded a three-year grant from the National Institute of Disability and Rehabilitation Research to study "The Effects of Endurance Exercise on Cardiovascular Conditioning in Post Polio Patients."

The second year of the study has been completed. Richard Owen, M.D. will report on this research at the Fifth International Polio & Independent Living Conference on Thursday morning, June 1, in St. Louis.

New Post-Polio Clinics

Biddeford, ME: Kathryn Seaholtz, M.D., University of New England, Biddeford, ME 04005. (207/283-0171 ext. 392).

Kansas City, MO: Lester S. Garfinkel, M.D., F.A.C.P., The Rehabilitation Institute, 3011 Baltimore, Kansas City, MO 64108. (816/756-2250).

Information on...

Polio Vaccine

Lederle Laboratories has completed the first clinical trials of a new inactivated ("killed") formulation of the three attenuated Sabin strains of poliovirus vaccine (Sabin trivalent IPV).

A recent issue (April 7, 1989, Vol. 38, No. 13) of Morbidity and Mortality Weekly Report features a revision of the 1983 statement of "General Recommendations on Immunization" by the Immunization Practices Advisory Committee (ACIP). Single copies are available for \$2 from Massachusetts Medical Society, C.S.P.O. Box 9120, Waltham, MA 02254-9120.

Fibromyalgia Syndrome

International Polio Network has received a few letters from polio survivors being diagnosed as having fibromyalgia (fibrositis, myofascial pain, and fibromyositis). Listed below are the most recent resources.

The British Journal of Medicine (February 25, 1989, Volume 298) features an article by Muhammad B. Yunus, "Fibromyalgia syndrome: new research on an old malady."

Dr. Yunus states, "...the first detailed and controlled study of the clinical characteristics of this syndrome was not published until 1981. Nevertheless, features are now well recognized, the most important and common being generalised pain, fatigue, and disturbance of sleep.

"The important abnormality on physical examination is the presence of multiple and consistent tender points, and the results of the usual laboratory tests are normal.

"The primary fibromyalgia syndrome should be diagnosed on the basis of

its own characteristic features and not by exclusion alone."

Dr. Yunus is an Associate Professor of Medicine, Dept. of Medicine, Section of Rheumatology, University of Illinois College of Medicine at Peoria, Box 1649, Peoria, IL 61656.

Other articles about fibromyalgia include:

"Research in Fibromyalgia: Past, Present, and Future" by D.L. Goldberg. Journal of Rheumatology, June 1988, Vol. 15, No. 6. Pages 992-6.

"The Concept of Primary Fibromyalgia (Fibrositis): Clinical Value, Relation and Significance to Other Chronic Musculoskeletal Pain Syndromes" by G.A. McCain, et al. Pain, June 1988, Vol. 33, No. 3. Pages 273-87.

"Fibromyalgia Among the Elderly. Comparison with Younger Patients" by M.B. Yunus, et al. Journal of the American Geriatrics Society, November 1988, Vol. 36, No. 11. Pages 987-95.

Vocational Rehabilitation

Delbert Lewis' article about vocational rehabilitation (VR) in the Winter Polio Network News prompted many positive responses. It appears that VR counselors in many regions are very "tuned in" to the late effects of polio. If you were denied services back in the 1960s, contact them again -- VR has changed. Support group leaders are encouraged to contact the VR office in their area to open the lines of communication.

Conference Tapes

The Fifth International Polio & Independent Living Conference, May 31-May 4, 1989, will be taped (audio and video). The order form is on pages 7 & 8 of this newsletter.

FIFTH INTERNATIONAL POLIO & INDEPENDENT LIVING CONFERENCE
MAY 31 - JUNE 4TH, 1989
SHERATON-ST. LOUIS HOTEL, ST. LOUIS, MO.

AUDIO & VIDEO CONVENTION TAPES

	Audio Cassette	VHS $\frac{1}{2}$ " Video
<u>Tape #1</u> - Impact of Natl. Policy on Independent Living: International Case Studies 2-Tape Session Date: 5-31-89 Time: 8:30 a.m. - 11:45 a.m.	_____	_____
<u>Tape #2</u> - What Really Limits Us? Elevating Everyone's Expectations 2-Tape Session Date: 5-31-89 Time: 1:30 p.m. - 4:45 p.m.	_____	_____
<u>Tape #3</u> - International Progress Reports: Networking and Research 2-Tape Session Date: 6-1-89 Time: 8:30 a.m. - 11:45 a.m.	_____	_____
<u>Tape #4</u> - Prescription for Fatigue, Underventilation, and Weakness 2-Tape Session Date: 6-1-89 Time: 1:30 - 4:45 p.m.	_____	_____
<u>Tape: #5</u> - Prescription for Pain, Exercise, and Energy Conservation 2-Tape Session Date: 6-2-89 Time - 8:30 a.m. - 11:30 a.m.	_____	_____
<u>Tape #6</u> - Psychological Adjustment: Several Points of View Including Yours 1-Tape Session Date: 6-2-89 Time: 1:30 p.m. - 3:30 p.m.	_____	_____
<u>Tape: #7</u> - Ethical Theory, Medical Care, & Life and Death Decisions 1-Tape Session Date: 6-3-89 Time: 8:30 a.m. - 9:30 a.m.	_____	_____
<u>Tape #8</u> - Mutual Decision-Making In Life & Death Situations 1-Tape Session Date: 6-3-89 Time: 10:00 a.m. - 11:45 p.m.	_____	_____

HOME MECHANICAL VENTILATION WORKSHOP

<u>Tape: #9</u> - Ventilation Problems & Solution of Anesthesia, Tracheostomies, Sleep and Swallowing-Related to Polio, S.C.I. 1-Tape Session Date: 6-3-89 Time: 1:30 p.m. - 3:00 p.m.	_____	_____
<u>Tape #10</u> - Muscular Dystrophy - Informed Choices 1-Tape Session Date: 6-3-89 Time: 3:00 - 4:00 p.m.	_____	_____
<u>Tape #11</u> - Home Ventilator Maintenance 1-Tape Session Date: 6-3-89 Time: 3:00 p.m. - 4:00 p.m.	_____	_____

	Audio Cassette	VHS ½" Video
<u>Tape #12</u> - Travel With Ventilators 1-Tape Session		
Date: 6-3-89	Time: 3:00 p.m. - 4:00 p.m.	
<u>Tape #13</u> - Home Ventilation in Children & Adolescents 1-Tape Session		
Date: 6-3-89	Time: 3:00p.m. - 4:00 p.m.	
<u>Tape #14</u> - Demonstrations of New Face Masks, Cpaps and Glossopharyngeal (Frog) Breathing) 1-Tape Session		
Date: 6-3-89	Time: 4:00 p.m. - 5:30 p.m.	

INFORMATION FOR ORDERING CONFERENCE TAPES

Please indicate which tape you would like by putting an X on the proper line to the right of each tape title. The cost of each two tape session is \$12.00. Single Tape Sessions are \$7.00. The cost of each video cassette tape is \$15.00. Please add \$2.50 for postage and handling of your order. Please fill in the address of the person who is to receive the tapes below. NOTE: Large orders may require additional shipping cost.

NAME: _____

STREET: _____

CITY & STATE: _____

ZIP CODE: _____

PHONE: _____

Please make check payable to: St. Louis Audio Visual, Inc.

Mail order and check to: St. Louis Audio Visual, Inc.
2114 Schuetz Road
St. Louis, Missouri 63146

OR Phone: (314) - 993-3388 - Tim North

We also except American Express and Mastercard.

SPECIAL DISCOUNTS

1. One free double audio session if all tape sessions are purchased.
2. One free single tape if all Saturday workshop tapes are purchased.

DID YOU
HAVE
POLIO



(OR DO YOU
KNOW SOMEONE
WHO DID?)

NATIONAL POLIO AWARENESS WEEK
MAY 29 - JUNE 4, 1989

CONTACT:

INTERNATIONAL
POLIO NETWORK
4502 MARYLAND AVENUE
ST. LOUIS, MISSOURI 63108 U.S.A.
314/361-0475

Americans With Disabilities Act

By Judy Heumann and Marilyn Golden

Stories about the discrimination we as disabled people face every day are very powerful. We must tell these stories in order to enable people to understand how significantly discrimination affects us every day in our lives. We must tell these stories in order to enable members of Congress, the media, our local communities, and other disabled people to know that we are fighting for full equality in this country. We must make it clear to all, including ourselves, that we want full and equal opportunities in all aspects of our lives and we will settle for nothing less.

It is difficult to write about the discrimination we face every day. It is difficult because many of us have stopped believing that we have the same rights as non-disabled people. We have accepted the lack of accessible buses, taxicabs, movie theaters, restaurants, public shopping malls, the denial of jobs, the inability to get adequate interpreter services, reader services, accessible religious institutions, as a reality in our lives because we have a disability. Many of us have not stopped to think how we would be living our lives if we didn't have a disability. It is time that we document how discrimination adversely affects our lives.

For too long we have equated equality with our ability to return tax dollars to the American economy. Now we must equate equality with our ability to function in our communities on a day-to-day basis like all other people. Now we must document all of the barriers that exist in our daily lives and prohibit us from partaking of the American dream.

We as disabled people, family members, or people working with

people who have disabilities experience directly and indirectly the effects of discrimination on a regular basis. All people, disabled and non-disabled, must participate in helping to educate all segments of our community about discrimination. We urge you to write about the discrimination you face every day when writing your letters to members of Congress.

The Americans with Disabilities Act is the most important piece of anti-discrimination legislation to come before the Congress since Section 504. It will not pass unless every person commits him or herself to its passage. You must make people understand the types of discrimination we face. Each one of us must tell our story. Our stories and hard work to improve our lives will result in the passage of the ADA.

Be creative! Members of Congress want to hear about what has happened to you and your friends. Write to your member of Congress and Senators at the following addresses:

The Hon. _____
U.S. House of Representatives
Washington, DC 20515

The Hon. _____
U.S. Senate
Washington, DC 20510

* * *

A 33-minute edited version of the September 27th (1988) House-Senate hearing on the ADA and discrimination on the basis of disability is now available. It can be shown at meetings and conferences but cannot be rebroadcast. It is open-captioned on a VHS tape. Cost is \$10.50 (includes postage) per tape. Contact Liz Savage or Donna Ledder, Epilepsy Foundation of America, 4351 Garden City Drive, Landover, MD, 20785. 301/459-3700.

POTPOURRI

Assistance with Pumping Gas

Amoco Oil Company and its participating Amoco dealers have introduced a program to assist physically disabled motorists with gasoline purchases.

Amoco dealers offering the Handicapped Service Program have agreed to pump gasoline for disabled motorists at designated self-serve islands, and charge them the self-service price. Motorists can identify Amoco locations offering the service by looking for the nationally-recognized handicapped logo--a person in a wheelchair. These signs will be posted in windows of participating stations and at the designated self-serve pump islands.

The program has been made available nationwide to all Amoco dealers and jobbers who have driveway attendants. To participate, dealers purchase a kit which includes a window sign so physically disabled motorists can identify the station as a participating location, pump island signs that indicate where the disabled motorist is to receive the service, and a supply of visor signs to be displayed by individual disabled drivers.

Besides the special wheelchair logo license plate, the visor card can also be used to identify the disabled for this program. The card contains a space for a doctor's signature, which authorizes "Service for the Handicapped" nationwide.

Motorists without handicapped license plates can obtain a visor card by showing an Amoco dealer an I.D. or other card certifying their disability. Disabled motorists should prominently display the visor sign each time they wish the service to be furnished, look for the handicapped service island, and notify dealers of their presence by honking their horn.

Video Available

Coping Successfully with Polio's Late Effects, a videotape for polio survivors, their families, their friends, and their professional care providers is available from The Post-Polio Research and Training Program, NIIA09-0491 300 N. Ingalls Building, Ann Arbor, MI 48109-0491.

This 20-minute production, authored by Sunny Roller, M.A. and Frederick M. Maynard, M.D., features a panel of five persons with the late effects of polio candidly discussing their new health problems and how they successfully cope.

The tape is available on 1/2" video cassette for \$50 and 3/4" video cassette for \$75. Payment in advance is required. Make checks payable to U of M Post-Polio Research Fund and allow 4-6 weeks for delivery.

Attendees of the Fifth International Polio & Independent Living Conference will be able to preview this video Sunday, June 4, 1989, during a Special Interest Workshop.

Attention: Artists

The National Rehabilitation Information Center invites artists with disabilities to exhibit and sell their work at the Center. NARIC has established an ongoing arts exhibition program which began in Winter 1988 with a multimedia exhibition loaned by the National Very Special Arts Office.

Each exhibition will be at the artist's convenience for an indefinite period of time. NARIC cannot pay shipping charges, but will cover the return costs. In order to reserve space and plan a display, write with the following information: date to be sent; number of pieces; a description, including size and price of each piece; if a piece sells, to whom checks should be made; and return date.

Send correspondence to: Laureen Summers, 8455 Colesville Road Suite 935, Silver Spring, MD 20910; 800/346-2742 or 301/588-9284.

Attention: Authors

Members and members to be of the International Brotherhood of Authors-in-Wheelchairs are invited to attend the first conference to be held at hotel Porto-Rio in Patras, Greece, September 1-5, 1989. Contact: Mr. C. Minas, Tentative Chairman, International Brotherhood of Authors-in-Wheelchairs, 87, Patron-Pyrgou Street, Tsaousi, Achaia, Greece.

Can You Help?

A polio survivor who also has Parkinson's Disease would like to share information with others in the same situation. If you are interested, send your name and address to IPN, 4502 Maryland Avenue, St. Louis, MO 63108.

Organizations

Breaking New Ground Resource Center provides technical assistance to physically-disabled farmers and agricultural workers. For additional information, including a newsletter, contact Lauri Logan, Breaking New Ground Resource Center, Dept. of Agricultural Engineering, Purdue University, West Lafayette, IN 47907. 317/494-5088.

* * *

For more information about an information network providing assistance to travelers with disabilities contact: Travelin' Talk, 1501 Broadway, Paducah, KY 42001.

* * *

The National Disability Action Center (NDAC), a new advocacy organi-

zation in Washington, DC, will represent people with physical and mental disabilities who have been subjected to exclusion, segregation, or any other form of discrimination.

For more information about NDAC, contact Timothy M. Cook, Director, NDAC, 2021 L Street, NW, Suite 800, Washington, DC 20036. 202/467-5730 (voice/TDD).

Publications

I have Seen and Touched and Tasted Life is a collection of Patricia O'Brien's writings, poetry, photography, and reflections of her friends. Patricia, a respiratory-dependent quadriplegic, died in May of 1988. To receive this 140-page book, send \$10 to Sharon Wallace, 1304 McLean, Royal Oak, MI 48067.

The Psychology of the Physically Ill Patient: A Clinician's Guide is based on clinical experience and a review of the current research in the literature. (The book includes 20 pages of references and a chapter on post-polio.) The author, Margaret E. Backman, PhD, is a Clinical and Health Psychologist with special training and experience working with the emotional difficulties arising from physical illness. To order send a check made out to Plenum Press for \$30.90 to Plenum Publishing Company, #33 Spring Street, New York, NY 10013.

* * *

For a single copy of the publication, "A Profile of Older Americans: 1988," write A Profile of Older Americans: 1988, AARP, P.O. Box 2240, Long Beach, CA 90801.

Updated every year, this publication has statistics, maps, charts, and graphs, that clearly illustrate the composition of today's Americans aged 65 and older.

Publications (continued)

A new handicapped product directory, The Illustrated Directory of Handicapped Products, is a photographic buying guide showing approximately 1,000 photographs with captions of products designed to aid persons with a disability.

The products are organized into 16 different categories for ease of use by the reader. Each product has a 50-75 word caption describing the product's features. Manufacturers' addresses and phone numbers (including toll-free 800 numbers when available) are included along with a listing of manufacturers arranged by type of products made.

To order a copy, send \$12.95 with name and address to Directory, 497 Cameron Way, Buffalo Grove, IL 60089.

Personal

After another week in the hospital, Gini Laurie is home again. She appreciates the thoughtful messages that arrive daily from all over the world.

Rehabilitation Gazette

The 30th Anniversary edition of the Rehabilitation Gazette has gone to press. Subscribers and G.I.N.I. members will soon be receiving their copy. Thank you for your patience.

IPN Membership Renewal Notices

In April, IPN mailed renewals notices to individuals whose memberships are due this quarter. Please return the card with a check for \$8 so you will receive the Summer Polio Network News (Vol. 5, No. 3).

National Polio Awareness Week

Congressman Richard A. Gephardt, Democrat from Missouri, will place the proclamation for National Polio Awareness Week (May 29-June, 4, 1989) in the hopper on April 25, 1989. Thanks to all of you who helped make this happen by contacting your legislator. His aide was very impressed with the response. (We will provide the complete list of co-sponsors as soon as possible.)

IPN would like to thank Ruth Bell (MD), Elaine Burns (MA), Beth Fenningkoh (WI), David Kelly (CA), Connie Mallory (WA), her daughter Michelle (DC), Kit McMinn (NC), and Jacoba Schneider (TX) for their cooperation and assistance in this endeavor.

Please help educate the public and other polio survivors by displaying the complimentary poster contained in this issue of the Polio Network News.

Extra posters were ordered and will be distributed for \$1 each (includes postage) until we run out. If you would like to order more, contact our office by phone.

The following state and local governments declared National Polio Awareness Week:

New Mexico, Garrey Carruthers, Governor

South Lake Tahoe, CA, Dr. Frank Hembrow

Carson City, NV, Marv Teixeira, Mayor

Reno, NV, Peter J. Sferrazza, Mayor

Sparks, NV, James L. Spoo, Mayor

Douglas Co., NV, Michael E. Fischer, Commissioner

Post-Polio Directory — 1989

IPN will now publish additions, deletions, and changes in the Spring, Summer, and Fall issues of the Polio Network News. The annual directory will be published and distributed with the Winter (February) issue. At that time all listings will be asked to complete a form and to return it to IPN. If IPN does not receive the form by the deadline, your listing will be deleted.

Because your name is listed in the Post-Polio Directory, you may receive requests to participate in research, to buy products, and to cooperate in fund-raising schemes. Please be cautious. A few group leaders have reported "suspicious" phone calls. Be leary of giving out names, addresses, and phone numbers of your members.

IPN has been asked by some states to list only the state organization. Our current policy is to list all groups regardless of size, affiliation, or philosophy. If you have any thoughts, pro or con, contact Joan Headley at IPN.

Please make the following CHANGES in the Post-Polio Directory -1989.

CLINICS

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Please ADD the following:

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Post-Polio Support Group
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Valparaiso, IN 46383

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Doris Benedict
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Helen Horn
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Harpursville, NY 13787
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Wyncote, PA 19095
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Central Virginia Post-Polio SG
Easter Seal Society of VA
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Gail Genereau
Appleton-Fox Cities Area
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Appleton, WI 54915
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Calendar

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 17, 1989. Third Annual Maine Polio Seminar. Hyde
School, Bath, ME 04539. Contact: Ron Hanson, 5 Forest
Avenue, Winthrop, ME 04364.

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

September 15-16, 1989. First Colorado State-Wide Post-Polio
Syndrome Conference. Denver, CO. Contact: Mary Ann
Hamilton, 1185 South Williams Street, Denver, CO 80210.
302/722-6945.

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.