

POLIO NETWORK NEWS

Winter 1987

Vol.3. No.1.

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

IPN is coordinated by Gazette International Networking Institute (GINI), which has maintained a worldwide polio network since 1958.

EDITOR:
Judith Raymond

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

IPN ANNUAL MEMBERSHIP,
POLIO NETWORK NEWS, &
POST-POLIO DIRECTORY:
\$5 for polio survivors
\$15 for health professionals
(Add \$3 postage outside U.S. & Canada)

DEADLINE for Vol. 3,
No. 2, 1987: April 30.

NATIONAL POLIO WEEK, JUNE 1-7, 1987

Action is underway to proclaim National Polio Week, June 1-7, 1987, focusing on the Fourth International Polio and Independent Living Conference in St. Louis, June 4-7.

Representative Richard Gephardt of Missouri who recently announced his bid for the Democratic presidential candidacy, will introduce the proclamation.

Polio survivors in each state should request their governors to issue statewide proclamations for the same week. The proclamation reads:

"A resolution commemorating the week of June 1-7, 1987, as NATIONAL POLIO WEEK,

WHEREAS there are an estimated 300,000 polio survivors in the United States today, of whom 65,000-70,000 may experience polio's late effects; and

WHEREAS knowledge about the late effects polio is slowly spreading to the health care community and to the general public; and

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

WHEREAS the International Polio Network, in an effort to call attention to the problem and to provide accurate, factual information, will bring together in St. Louis on June 4-7, 1987, national and international experts on post-polio problems; now, therefore be it

RESOLVED by the House of Representatives (the Senate concurring) that the week of June 1-7, 1987, be hereby commemorated as NATIONAL POLIO 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 as a reflection of our respect for their work in this important area.

LETTERS TO THE EDITOR

Shock Absorbent Crutches

"I had polio in 1953, at age 2, and had residual paralysis in my left leg. Now I am developing problems in my shoulders, arms, and hands. I use crutches. Does anyone know of a shock absorbent crutch available on the market or a crutch that can be adapted?"

Wilma Shaver
Box 627
Sicamous, B.C.
V0E 2V0 Canada

ED: Yvonne Greatwood of Virginia sent us her idea for crutch pads that relieved the pain of crutch walking. Yvonne used regular polyfil quilt batting, doubled it over the crutch top, and then covered it all with fake fur. Write Yvonne, 1515 Great Falls St., Apt. 403, McLean, VA 22101.

Ob/Gynecologic Care of Women With Disabilities

"I am a third-year medical student at the University of Illinois, working on an independent research project concerned with OB/gynecologic care of women with disabilities. Women interested in filling out a questionnaire can send their name and address on a postcard."

Michelle Gittler
1506 W. Polk St., #1R
Chicago, IL 60607

Send your "Letters to the Editor" to International Polio Network (IPN), 4502 Maryland Ave., St. Louis, MO 63108 by April 30, 1987.

SOCIAL SECURITY ACTION DELAYED

The proposed revisions to the Program Operations Manual System and a Program Circular on post-polio have been delayed.

The Social Security Administration (SSA) still intends to issue both guides, and wants to reassure polio survivors that SSA does already have medical criteria for polio and that claims of polio survivors are being processed.

The local Social Security office is the appropriate resource for polio survivors having questions about a disability claim, NOT headquarters offices in Baltimore. (Polio Network News, Vol 3., No. 2, 1987, will contain more details.)

POST-POLIO ANTHOLOGY

Poetry, short stories, and essays by polio survivors are wanted for an anthology to be submitted to a prospective publisher. Topics may include humor, personal growth, sensuality/sexuality, dreams, relationships, family life, etc. Focus of the work need not be polio-related.

Up to three manuscripts may be submitted per author, typed in triplicate and doublespaced. Include a brief biosketch - year of polio onset, disability, occupation, etc. Authors may remain anonymous. No manuscripts will be returned.

Deadline is June 30, 1987. Send self-addressed stamped envelope for notification of acceptance or rejection. Submit all work to Barbara Rubel Pike, 3448 Brookline Ave., Cincinnati, OH 45220. Coeditors are Charlene Bozarth and Sunny Roller of the Polio Network of Michigan.

MORE ON PLASTIC BRACES

"The Orthotic Dilemma" by Laura K. Smith, PT, PhD, appeared in the Summer 1986 issue of Polio Network News, discussing the advantages and disadvantages of plastic braces orthoses. Recently, Glenn Ham-Rosebrock, C.O., of Orthomedics in Los Angeles, offered his experience with plastic.

"I am a certified orthotist (C.O.) with a large practice of over 500 polio survivors.

"I contracted polio at age five months and stayed at Shriner's Hospital in San Francisco until age two. I was braced in bilateral long leg braces until age seven, when I progressed to a single long right leg brace and an ankle foot orthosis on the left leg.

"I attended UCLA's orthotic program and interned at Rancho Los Amigos Hospital. As both a student and professional patient, I knew there had to be better way.

"The introduction of the first polypropylene ankle foot orthosis and then the knee ankle foot orthosis as a molded footshell allowed independent footwear - a great benefit in weight reduction for the wearer. The orthotist benefited also by controlling the foot and ankle complex that had become lost inside a high-priced orthopedic shoe no one wanted to wear anyway.

"However, casting jigs and forms for thigh shells would not fit the atrophied thigh tissue of polio survivors. Special hand-held casting procedures were used to get a negative mold; then, a tedious modification session would follow to finish a positive cast.

"Once the polypropylene shells were vacuum formed and trimmed, and ready for fitting, the truth was finally known - either it was the wrong measurement

sheet or it was turning out NOT to be the better way.

"I tried a practical approach to the problem. I did not use the conventional leather cuffs and metal bands or the quadrilateral shells that are designed to use muscle groups as purchasing forces.

"I used the principle of the polio survivor's lack of thigh tissue density, redistributing tissue to provide unity between the person's flail extremity and the orthosis.

"I compress the tissues from medial to lateral to create an increased anterior/posterior dimension directly opposite the quad brim. I create a pocket posteriorly, identifying the medial and inferior border of the ischium. While maintaining the person's foot in the line of progression desired, I also identify the trochanter anterior and posterior borders.

"The finished shell is above the trochanter for suspension. Posteriorly, a padded channel of the person's own tissue is used to protect the shaft of the femur.

"I have applied hundreds of the thigh shell design to polio survivors with only one failure."

Address: Glenn "Henry"
Ham-Rosebrock, C.O., Ortho-
medics, 2500 S. Flower,
Los Angeles, CA 90007.
213/749-7184.

PPMA Study

Raymond Roos, MD, Director of the Post-Polio Clinic and the Motor Neuron Disease Center, University of Chicago, reports on an electromyography (EMG) and muscle biopsy study recently completed by Drs. Cashman, Maselli, Wollmann and Roos. Patients studied were those with the rare form of the late effects of polio - post-polio progressive muscular atrophy (PPMA).

"We found evidence of on-going nerve damage in patients with this syndrome as well as in stable non-weakening 'control' patients with a history of paralytic polio.

"One study suggested that no laboratory test at present can be used to diagnose PPMA and that evidence of progressive nerve damage is frequently seen decades after poliomyelitis.

"Apparently the 'controls' are able to reinnervate the damage and avoid motor functional difficulties....

"Our investigations of the motor nerve suggested that the terminal sprouts which synapse on the muscle (i.e., the neuromuscular junction) may be injured or dying in PPMA.

"This hypothesis is a popular one and has been proposed by other groups as well as ours. However, there is no study actually examining the neuromuscular junction and terminal sprouts in PPMA."

Dr. Roos would like volunteers diagnosed with PPMA for such a study. Write or call Roberta Martia, RN, Post-Polio Clinic, University of Chicago, BH Box 425, 5841 S. Maryland Ave., Chicago, IL 60637. 312/702-6221.

British Study of Late Sequelae of Poliomyelitis

The following abstract from Dr. Geoffrey Spencer, consultant in charge at St. Thomas' Hospital in London presents interesting data:

"Progressive functional deterioration following acute poliomyelitis can occur after a prolonged period of stability. We present follow-up data on 208 patients; the period from the original illness to December 1985 or death was between two and 73 years (mean 33.8 years).

"One hundred sixty-two (77.9%) patients developed late functional deterioration. This was due to purely respiratory factors in 99 cases, new neurological signs in 19 cases, and orthopaedic problems in 17 cases; 27 patients deteriorated due to a combination of factors.

"The commonest cause of respiratory deterioration was the development of alveolar hypoventilation in association with progressive scoliosis. Eighty-five patients needed respiratory support commencing between one and 66 years (mean 28.2 years) after the acute illness.

"New neurological signs were due to a clearly defined cause in each of the 19 patients. No cases of motor neurone disease or post-polio muscular atrophy were identified.

"This study shows that late sequelae following poliomyelitis are common. The major causes of functional deterioration may be treatable and even avoidable."

Write Geoffrey Spencer, OBE, MB, BS, FFARCS, St. Thomas' Hospital, Phipps Respiratory Unit, South Western Hospital, London SW9 9U, England.

Servicemen in WWII Wanted
for Post-Polio Study

Dr. H.V. Wyatt of Leeds, a researcher on the late effects of polio needs to trace servicemen who contracted polio during World War II.

Dr. Wyatt recently published a nontechnical account of "Priests and Polio - Research in a Warmhearted Climate" in the British Medical Journal.

Dr. Wyatt has tracked over 1,000 cases of polio in Malta and spent 3 months in 1985 in India studying polio.

Write Dr. Wyatt, 1 Hollyshaw Terrace, Leeds LS15 7BG England.

Acupuncture Results

Dr. Dennis Galvon of Victoria, British Columbia, has begun a second study on the therapeutic effects of acupuncture for polio survivors.

Patients had clear histories of paralytic residuals of polio and reported pain in the back, shoulder, and leg. Ages ranged from 44 to 70 years. Results included general relaxation, better sleep, decreased pain, and more energy.

Write or call Dr. Galvon, #303 - 1711 Cook St., Victoria British Columbia V8T 3P2 Canada. 604/385-4141.

CHANGE OF ADDRESS??

Polio Network News will NOT be forwarded by your post office. Please advise if you are moving - send both old and new addresses.

Polio Information in Chinese

Edited by polio survivor Rev. Bob Ronald, S.J., and funded by a grant from the Rotary Club of Taipei-Tienmou, Care of Polio-myelitis is an 80-page booklet in Chinese.

Contents include the late effects of polio, rehabilitation and exercise, six principles of living with polio, selection and maintenance of braces, coping with polio, vocational rehabilitation after polio, standards for a wheelchair environment, and a list of resources.

Helpful hints for parents of post-polio children and for polio survivors who are parents are two additional sections.

For more information write Operation De-Handicap, P.O. Box 7-553, Taipei, 10610, Taiwan (R.O.C.).

Norwegian Polio Survivors

Utgitt av Norges Handikapforbund is an organization of persons with disabilities in Norway which sponsors a polio group called Utvalg for Polioskadde.

The group publishes a quarterly magazine - Post Polio: Tidsskrift for Polioskadde. Norwegian polio survivors will be attending the 1987 polio conference.

Write Turid Josang, Norges Handikapforbund, Boks 49 Bryn, 0611 Oslo 6 Norway.

International Post-Polio
Directory 1987 Available

New edition available - write International Polio Network, 4502 Maryland Ave., St. Louis, MO 63108 U.S.A.

**POLIO SURVIVOR JUSTIN DART, JR.,
NEW COMMISSIONER OF REHABILITATION
SERVICES ADMINISTRATION (RSA)**

Justin Dart, Jr., was sworn in as the tenth commissioner of the federal rehabilitation program on September 3, 1986, to head a \$1 billion program annually serving over 1 million persons with disabilities.

Disabled by polio at age 18, and a wheelchair user since 1948, Dart has been active as an advocate for the rights of individuals with disabilities for more than 20 years.

Dart has served on the Texas Council on Disabilities and the National Council on the Handicapped.

Dart says, "I will work hard to influence public understanding of the rights and potential of people with all types of disabilities....We who are associated with rehabilitation...have an inescapable responsibility to take positive action."

Dart's address at RSA is 400 Maryland Ave., S.W., Washington DC 20202.

**PATHOLOGIC STUDY OF SPINAL
COLUMNS OF POLIO SURVIVORS**

In the last issue of Polio Network News it was reported that the Armed Forces Institute of Pathology (AFIP) was developing a protocol for organ donations from polio survivors.

Regrettably, governmental bureaucracies have delayed development of this protocol. Polio survivors interested in willing their bodies to the AFIP for research on the pathology of the spinal cord and brain stem should write to G.H. Pezeshkpour, MD, Chief, Neuromuscular Pathology, AFIP, Washington DC 20306-6000.

WORLD HEALTH DAY: APRIL 7

"Healthy Living: Everyone a Winner" is the theme of World Health Day 1987, with special emphasis on immunization. Sponsored by the American Association for World Health (AAWH), the U.S. Committee for the World Health Organization (WHO), World Health Day is observed in 166 countries and the United States.

The preventive aspect of immunization for all citizens is WHO's goal by the year 1990. From preschoolers to senior citizens, the underutilization of immunization costs millions of lives.

POST-POLIO BIBLIOGRAPHY

Recently published:

"Late Effects of Poliomyelitis" by James Cosgrove, MD, and Michael Alexander, Ellen Kitts, Barbara Swan, Milton Klein, and Roberta Bauer. Archives of Physical Medicine & Rehabilitation, January 1987, Volume 68. Pages 4-7.

Aging with a Disability by Roberta Trieschmann, PhD, 1986, New York, Demos Publications, \$17.95. The issue of aging with a disability as a new problem for western societies. Personal interviews with individuals disabled at least 30 years and experiencing some life changes associated with aging.

Videotape available on the late effects of polio as discussed by Jason Daube, MD, Mayo Clinic, and Raymond Roos, MD, University of Chicago Medical Center, at annual meeting of National Easter Seal Society. Send \$20 to Easter Seal Rehabilitation Center of Mobile, 2419 Gordon Smith Dr., Mobile, AL 36617.

G.I.N.I.'S FOURTH INTERNATIONAL POLIO & INDEPENDENT LIVING CONFERENCE

June 4-7, 1987
Sheraton St. Louis Hotel
St. Louis, Missouri

Wednesday, June 3, 1987

7:00 p.m. - 9:30 p.m.
Preregistration and DESSERT BUFFET

Thursday, June 4, 1987

8:00 a.m. - 5:00 p.m.
Registration/Exhibits

Late Effects of Polio: Symptoms

9:00 a.m. Muscle Weakness
11:15 a.m. Fatigue
12:45 p.m. LUNCH
2:00 p.m. Pain
3:45 p.m. Sleep, Breathing and Swallowing Problems
6:30 p.m. DINNER
8:00 p.m. Disability Rights: Past, Present, and Future

Friday, June 5, 1987

8:00 a.m. - 4:00 p.m.
Registration/Exhibits

Late Effects of Polio: Treatment and Research

9:00 a.m. Exercise, Weight Control, and Nutrition
11:00 a.m. Bracing, Mobility, and Seating
12:30 p.m. LUNCH
Speaker: William Rea, MD
"Environmental Influences"
2:00 p.m. Research/Polio Immunization
6:00 p.m. Friday Night at St. Louis Union Station

Saturday, June 6, 1987

8:00 a.m. - 5:00 p.m.
Registration/Exhibits
8:30 a.m. - 10:00 a.m.
CONTINENTAL BREAKFAST
8:30 a.m. - 10:00 a.m.
Polio Support Group Leaders Workshop
8:30 a.m. - 10:00 a.m.
Polio Clinic Physicians Roundtable

Coping

10:00 a.m. The Psychology of Disability
11:00 a.m. Coping Relationships: Spouses, Parents,
Friends, and Attendants
12:30 p.m. LUNCH
Speaker: Roberta Trieschmann, PhD
"Aging and Disability"

2:00 p.m. Coping with Stress Management
3:30 p.m. Coping with Employment/Unemployment
4:30 p.m. Coping with Health Insurance
6:30 p.m. Reception for Justin Dart, Jr.,
Ted Kennedy, Jr., Edward Newman, PhD,
and James Roosevelt
7:30 p.m. Banquet in Celebration of the
10th Anniversary of 504
9:30 p.m. DISCO

Sunday, June 7, 1987

8:00 a.m. - 12:00 p.m.
Registration/Exhibits
8:00 a.m. - 9:00 a.m.
CONTINENTAL BREAKFAST

Independent Living

9:00 a.m. Lessons from American Experiences with
European Independent Living
(World Rehabilitation Fund Fellows)
10:00 a.m. Cultural Attitudes Toward Disability
and Independent Living Worldwide
12:30 p.m. LUNCH
2:00 p.m. Cultural Attitudes Toward Disability
and Independent Living Worldwide
4:00 p.m. Adjournment

Conference Coordinators

Gini Laurie
Judith Raymond

Honorary Advisory Committee

Justin Dart, Jr.
The Rt. Hon. the Earl of Dunraven
Ted Kennedy, Jr.
Itzhak Perlman
James Roosevelt
Albert Sabin, MD
Jonas Salk, MD
Geoffrey Spencer, OBE, MB, BS, FFARCS

ORGANIZED AND SPONSORED BY
Gazette International Networking Institute
(G.I.N.I.)

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

International Polio Network
4502 Maryland Ave.
St. Louis, Missouri 63108 U.S.A.
(314) 361-0475

Non-Profit Org.
U.S. Postage
PAID
St. Louis, MO
Permit No. 1711

Address Correction Requested

1987 CALENDAR

March 28. A Symposium on Post-Polio Syndrome. Forsyth Memorial Hospital, Winston-Salem, North Carolina. Contact: Ann Williams, North Carolina Easter Seal Society, 832 Wake Forest Rd., Raleigh, NC 27604. 1-800-662-7119.

April 10. Post-Polio Conference. Ramada Inn North, Phoenix, Arizona. Contact: Pat Caldwell, Arizona Easter Seal Society, 903 N. Second St., Phoenix, AZ 85004. 602/252-6061.

April 11. The Late Effects of Polio. Northwest Hospital, Tucson, Arizona. Contact: Ernie Anderegg, 8579 N. Calle Tioga, Tucson, AZ 85704. 602/742-7742.

April 11. Second Annual Meeting, Polio Network of Michigan. Plymouth Congregational Church, Lansing, Michigan. Contact: Charlene Bozarth, 4815 Arapaho, Okemos, MI 48864. 517/332-3789.

April 25. Abilities Expo/Post-Polio Workshop. Los Angeles Convention Center, Los Angeles, California. Contact: Polly Anderson, 210 S. Juniper, Suite 100, Escondido, CA 92025. 619/489-0450.

May 2. The Late Effects of Polio. Chattanooga Trade Center, Chattanooga, Tennessee. Contact: Dorma Farmer, 206 Ivy St., Rossville, GA 30741. 404/866-3779.

May 9. Post-Polio Conference. Sheraton Airport, Pittsburgh, Pennsylvania. Contact: Carrie Kaufmann, PhD, 1451 Barnsdale, #1L, Pittsburgh, PA 15217. 412/624-2868.

June 4-7. FOURTH INTERNATIONAL POLIO & INDEPENDENT LIVING CONFERENCE, SHERATON ST. LOUIS HOTEL. CONTACT: G.I.N.I., 4502 MARYLAND AVE., ST. LOUIS, MO 63108. 314/361-0475.

September 12. Post-Polio Conference. Chicago, Illinois. Contact: Roberta Simon, RN, 7835 Darien Pkwy., Darien, IL 60559. 312/969-0287.

September 18-19. Post-Polio Conference. Westlake Holiday Inn, Cleveland, Ohio. Contact: Margaret Meyer, SIL, 25100 Euclid Ave., Suite 105, Euclid, OH 44117. 216/731-1529.