

# POLIO NETWORK NEWS

Winter 1986

Vol.2. No.1.

An international newsletter for polio survivors and support groups, physicians and health professionals, and resource centers, in order to exchange information, encourage research, and promote networking among the post-polio community.

**Editors:**

Deborah Brewer  
Robert Gorski  
Gini Laurie  
Judith Raymond

**Guest Columnist:**

Harriet Bell

**Publisher:**

Gazette  
International  
Networking  
Institute  
(G.I.N.I.)

4502 Maryland  
St. Louis MO  
63108

314/361-0475



**March of Dimes**  
BIRTH DEFECTS FOUNDATION

1275 Mamaroneck Avenue, White Plains, NY 10605 914 428-7100

ARTHUR J. SALISBURY, M.D., MPH  
Vice President For Medical Services

October 28, 1985

Mrs. Gini Laurie  
Gazette International  
Networking Institute  
4502 Maryland Avenue  
St. Louis, MO 63108

Dear Gini,

The following information has been sent to Chapter Executive Directors and the field staff of the March of Dimes Birth Defects Foundation to guide their activities in the problem of post polio, muscle atrophy. This has been provided by Dr. Arthur J. Salisbury, Vice President for Medical Services.

To the extent that funds and staff time can be made available without reducing our primary focus on the prevention and amelioration of birth defects, Chapters should assist the formation and operation of support groups for affected persons and their families. Support groups are a mechanism for sharing problems, identifying resources for solutions and boosting morale.

Chapters can assist by

- arranging locations for meetings
- preparing and mailing notices of meetings and newsletters
- co-sponsoring with Easter Seal Society and/or rehabilitation facilities conferences open to affected persons, their families, health professionals and the general public for purposes of education and improved understanding
- providing access to the media to reach affected persons
- acting as a resource for referral to local medical (physicians and rehabilitation centers) and financial (Medicare, Medicaid, Social Security Supplementary Disability Income, Vocational Rehabilitation etc) assistance

Expenditures for the above activities should not exceed \$5,000 per year and should be recommended by the Health Professional Advisory Committee.

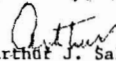
Given the magnitude of the problem of birth defects, it is not advisable for Chapters to assist in payment for inpatient or outpatient medical evaluation, physical therapy, medications or assistive devices such as wheel chairs and braces for persons affected by post polio muscle atrophy.

Headquarters will continue to support the service which provides respiratory equipment for persons who have previously or now newly require this equipment. This amounts to approximately \$500,000 per year.

Chapters receiving inquiries regarding research proposals should direct these to Dr. Samuel J. Ajl, Vice President for Research.

Your other questions should be directed to the Medical Services Department.

Sincerely,

  
Arthur J. Salisbury, M.D.

## POST-POLIO CLINICS

### Pitt Co. Memorial Hospital Greenville, North Carolina

Dr. Ulrich K. Alsentzer, a physiatrist, directs the post-polio clinic in Greenville which opened in January. Dr. Alsentzer is Medical Director of the Regional Rehabilitation Center, and Chairman of the Dept. of Physical Medicine and Rehabilitation at ECU School of Medicine. Dr. Alsentzer trained under the renowned Dr. Robert Bennett of Warm Springs.

The clinic provides physical therapy, occupational therapy, respiratory therapy, nursing, speech therapy, and psychological counseling.

Each discipline is allotted one hour for patient evaluation, after which a team conference is held to determine which patients need further testing and treatment.

Angie Angle, R.N., assists Dr. Alsentzer with clinic protocol. Address: P.O. Box 6028, Greenville, NC 27834. (919) 757-4313.

### University of Chicago Medical Center, Chicago, Illinois

At the University of Chicago's new polio clinic, Dr. Neil Cashman is developing criteria for determining which patients would respond to treatment directed toward improving the function of motor nerve supply to muscle or to treatment directed toward relieving chronic strain.

The clinic provides an occupational therapist, a physical therapist, a nutrition evaluator, and a social worker.

Patients are screened, and those with musculoskeletal problems are sent to the orthopedics department. Patients with progressive post-polio muscular atrophy are treated in a new program.

A typical work-up includes a general physical, a neurological exam, and a history of both original and post-polio experiences.

Pulmonary function tests are ordered only for those with either a history of respiratory involvement or those with evidence of new respiratory problems. Address: 5841 S. Maryland, Chicago, IL 60637. (312) 962-6221.

### Mercy Medical Center, Denver Colorado

Dr. Marny Eulberg, a family medicine physician and polio survivor herself, heads the post-polio clinic, assisted by a physical therapist and other specialists and consultants.

Dr. Eulberg takes a medical and rehabilitation history, tests muscles and assesses functioning, and plans follow-up visits. The clinic is currently open one morning per week.

Address: 1650 Fillmore St., Denver CO 80206. (303) 393-3778.

### The Institute for Rehabilitation and Research (T.I.R.R.), Houston Texas

Dr. Lauro Halstead has received a \$50,000 grant from NIHR to establish a model post-polio service project for polio survivors.

Support services will include expanded therapy services, assistive equipment, surgical interventions, weight reduction programs, monitored exercise programs, stress reduction programs, and other lifestyle modifications.

The project will also provide support services for personal care assistance, mobility aids, and financial aid for home and work site modifications. Address: 1333 Moursund Ave., Houston TX 77030. (713) 799-5909.

SOCIAL SECURITY DISABILITY  
INSURANCE BENEFITS

Marge Torre of the Philadelphia Post-Polio Support Group has been invited by the Social Security Administration Board to present the post-polio issue before the Board.

Many polio survivors have been denied disability insurance because officials at Social Security have no knowledge or understanding of the late effects of polio, nor do they realize the number of polio survivors with problems.

Torre is appealing for documented medical records and case histories from polio survivors who are unable to work due to the late effects of polio. Torre asks that a consent form be included with the documentation. Address: 7921 Fairfield St., Philadelphia PA 19152. (215) 332-5220.

\*\*\*

St. Louis Attorney Robert Crowe has prepared a six-page outline of Social Security disability benefits covering the different benefit categories, the four steps in the administrative procedure from filing a claim to the final federal court review, and continuing disability investigations.

The outline is available from G.I.N.I., 4502 Maryland Ave., St. Louis MO 63108 for \$1 plus a self-addressed stamped envelope.

\*\*\*

The National Organization of Social Security Claimants' Representatives is an organization of attorneys specializing in Social Security laws. Call 1-800-431-2804 to obtain the name of an attorney in your area.

Address: 19 E. Central, New York, NY 10965.

AMERICAN FOUNDATION FOR POST-POLIO  
RESEARCH (AFPR) by Doug Martin

Research is the focus of a new organization concerned with the late effects of polio. The American Foundation for Post-Polio Research was founded by the following:

President Douglas Martin, Ph.D.,  
Educator/Urban Planner;  
Vice-President Ruth Hall-Phillips,  
Assoc. Advocacy Director/Architect  
Paralyzed Veterans of America;  
Secretary Robert Gorski,  
Editor, Disabled USA;  
Treasurer Roger Shaffer,  
Educator;  
Membership Chairman Louis Rigdon,  
Attorney, US Government.

Through their involvement as consumers, the officers saw the need for an organization targeted on research. Goals are to encourage governmental and other groups to fund post-polio research, to promote interest in post-polio issues in the research community, to raise funds for research, and to cooperate with other groups and individuals with similar aims.

In late November, APFR alerted polio support group leaders and physicians about proposed funding priorities of the National Institute on Handicapped Research, one of which addressed post-polio. Support letters were to be submitted to NIHR by the end of the comment period in mid-December.

APFR also supports the Second Post-Polio Research Symposium at Warm Springs in September 1986. APFR encourages the scientific community to pursue intensive research efforts in developing appropriate treatment programs for polio survivors.  
Address: 4733 Bethesda Ave.,  
Suite 730, Bethesda MD 20814.

## POST-POLIO SUPPORT GROUPS AND CONFERENCES

### Michigan

Charlene Bozarth, Chair of Michigan's Polio Network, reports phenomenal success in reaching and organizing polio survivors around the state.

The Network evolved from the Late Effects of Polio Coalition, formed by Jo Strauss in 1984, and has a broad base of supporters including Easter Seals, March of Dimes, Kenny Michigan Rehabilitation Foundation, Physically Impaired Association of Michigan, and Michigan Legislative Assistants.

Attendance at their October conference on the late effects of polio drew over 300 polio survivors and health professionals.

The Network's goals include reaching polio survivors, providing psychological support, spurring the medical community to research the causes and treatment, and making the public aware of the problems polio survivors may face.

Membership in the Michigan Polio Network is \$5.  
Address: P.O. Box 14148, Lansing, MI 48901-4148. 1-800-292-2729.

### Nebraska

Nancy Carter of the Nebraska Polio Survivors Association reports that they have reached over 700 persons in Nebraska and organized seven support groups throughout Nebraska.

"We are planning a statewide polio conference in 1986 to educate the Nebraska medical community," says Carter.

The Association mails out information packets, maintains a library of post-polio literature, and refers polio survivors to health professionals.  
Address: P.O. Box 37139, Omaha, NE 68137. (402) 895-2475.

### Oklahoma

Coordinators Dianne Niemczyk and Dr. Marion Davis are enthusiastic about the response to the Polio Survivors Support Group of Oklahoma City.

"Since October, the group has swelled to 100, with polio survivors coming from around the state," states Niemczyk.

Monthly meetings have been informal with people just talking about the problems they are experiencing. Guest speakers are planned for future meetings.  
Address: Dianne Niemczyk, 3204 Hillside Dr., Del City OK 73115. (405) 672-8939.

### Connecticut

The Southern Connecticut Post Polio Support Group met with the Greater Bridgeport Medical Association, a group representing over 350 physicians, to provide information on post-polio.

The group's polio conference in June attracted over 200, and was co-sponsored by Gaylord Hospital, which also has a polio clinic.

In October, at a presentation to Gaylord Hospital staff and support group members, Dr. Theodore Munsat, Director of Neuromuscular Research, New England Medical Center, reported on experimental testing. Munsat has devised an assessment that will measure small incremental changes in muscle function of polio survivors.

Address: Judy Grosner, 175 Dahl Ave., Stratford CT 06497. (203) 375-6532.  
State Coordinator Ruth Gregory, 1830 Nichols Ave., Stratford CT 06497. (203) 375-5084.



## Wisconsin

"The Post-Polio Resource Group of Southeastern Wisconsin has held monthly meetings since spring," says Paulette Auclair of the Curative Rehabilitation Center in Milwaukee.

"Programs have focused on polio and infection, Social Security's disability claim process, clothing and environmental modifications."

Curative Rehabilitation Center assists the group and provides a polio clinic.

Address: Paulette Auclair, 1000 N. 92nd, Milwaukee WI 53226. (414) 259-1414, ext. 398.

## New York

Harriet Bell reports that "Post-Polio Update: Strategies for Coping with Severe Disabilities in Mid-Life," a conference sponsored by Howard A. Rusk Respiratory Center was held on November 15, 1985, at Goldwater Memorial Hospital on Roosevelt Island. It was attended by over 250 people, including Dr. Rusk, the "father of rehabilitation medicine."

Conference moderator Dr. Augusta Alba, the recipient of a lifetime achievement award for her dedication to people who have had polio, presented an overview of health management.

Dr. Matthew Lee, Director, Dept. of Rehabilitation Medicine, discussed the implications of polio treatment for other disabilities.

The Goldwater staff formed a health management panel on the physician's role; respiratory function, muscle strength, and exercise; fatigue; nutrition; psychological issues; access to home health services; and chemical dependencies.

The epidemiology and long-term effects of polio from 1935-1955 were examined by Dr. Mary Codd, special project associate, Dept.

of Medical Statistics and Epidemiology at the Mayo Clinic.

An independent living panel was moderated by Marilyn Saviola, of the Center for Independence of the Disabled of New York.

Address: 510 Main St., Suite A446, New York NY 10044. (212) 223-03523.

## Washington, D.C.

On October 26, 1985, the Post-Polio League for Information & Outreach, Inc., and the National Rehabilitation Hospital co-sponsored "Assessing the Needs of Post-Polios: A Working Conference."

The medical and health issues were presented by Drs. Goldschmidt, Toerge, and Aseff of the National Rehabilitation Hospital, Dr. Halstead from T.I.R.R., Dr. Speier of Sister Kenny Institute, Margaret Pfrommer of Northwestern University, Debby Brewer of the Post-Polio League, and Robert Gorski, editor of Disabled USA.

The participants later broke into small brainstorming groups and generated a list of medical, social, and psychological needs which should be addressed by a treatment program.

Address: Cameron Janish, 1089 Travis Lane, Gaithersburg, MD 20879.

## Quebec, Canada

Polio Quebec was founded in October 1985 by Sieglinde Stieda. Now numbering 200, the group plans to educate the medical community in Quebec about post-polio problems, as well as reach the estimated 4,000 polio survivors in the province.

The group also plans to translate G.I.N.I.'s Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors into French. Address: 3880 Plamondon St., Apt.10, Montreal Quebec H3S 1L9.

A PERSON OF ACCOMPLISHMENT:

RENAH SHNAIDER

by Debby Brewer

When Renah Shnaider enters a room, people take notice. Her striking appearance, lively mind, and warm manner bring a surge of energy to any setting. Renah reports that after her first severe post-polio experience she slowed down. Yet, Renah "slowed down" is still a dynamo.

She founded the first post-polio support group in the San Francisco area, presented two successful polio conferences, and indirectly contributed to the establishment of two post-polio clinics in the area. Though Renah is battling serious health problems, she is planning a third polio conference in 1986 for the East Bay.

Throughout her career, Renah has been an advocate and worker in the disability movement. While at Wayne State, where she earned a B.A. in sociology and psychology, and an M.A. in rehabilitation counseling, she successfully petitioned the university administration to make curb cuts on campus.

The California Department of Rehabilitation recruited Renah in 1963. Renah later worked as a disability evaluation analyst for the California Department of Health.

Because she was so much on the go, so much involved in her work, Renah didn't consciously acknowledge the increasing pain and fatigue she was experiencing. Then, in 1976, thirty-two years after the onset of polio, Renah found herself unable to move. "I was in my wheelchair in front of a jewelry shop, and simply could not continue. The owner of the shop came out, pushed me to my car, and helped me in. I was able to drive home, but once there, I couldn't get myself out of the car," Renah recalls. Eventually a neighbor came home, found Renah, helped her in, and

called for medical aid.

At the hospital physicians and physical therapists examined and "treated" Renah. "They knew nothing about polio. They treated me for arthritis. After a week I was no better."

Renah was referred to Dr. Stanley Yarnell, a physiatrist at St. Mary's Hospital. Yarnell had never seen a polio survivor before, but had studied under Dr. Ernest Johnson at Ohio State who had described new health problems in polio survivors. Dr. Yarnell diagnosed post-polio syndrome and degenerative arthritis.

Then an emotionally exhausting period ensued for Renah. She had to unlearn all her old patterns and learn new ones. "I was embittered and depressed," she says. "I had to change from being superactive to being totally restricted."

Slowly Renah regained her strength and learned to conserve energy. She began using a motorized wheelchair.

Renah decided to diffuse her anger by working for the post-polio community. She became Dr. Yarnell's "lay expert."

Between the two conferences Renah organized in 1981 and 1984, Dr. Yarnell opened a post-polio clinic at St. Mary's and Renah started a support group which later split into one in San Francisco and one in the East Bay.

"We decided not to incorporate, not to go to a formal structure, but to just come together and talk . . . California style. We discuss issues that concern everybody. When new people join, they first tell their own story. Then we each offer an opinion and ideas for medical care, resources, devices, anything that might help," states Renah.

Renah describes her present lifestyle as "laid back," but she is still a catalyst for the post-polio community in the Bay area.

Address: 350 Vernon, Apt. 101, Oakland, CA 94610.

POST-POLIO PUBLICATIONS

Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors, edited by Gini Laurie, Frederick Maynard, M.D., D. Armin Fischer, M.D., and Judy Raymond. c1984. \$6 postpaid, \$7 (outside US). Available from Gazette International Networking Institute (G.I.N.I.), 4502 Maryland Ave., St. Louis, MO 63108. (314) 361-0475.

Rehabilitation Gazette's 2nd International Post-Polio Conference and Symposium on Living Independently with Severe Disability, May 6-8, 1983, St. Louis, edited by Gini Laurie and Judy Raymond. c1984. \$16 postpaid, \$17 (outside US). Also available from G.I.N.I.

Rehabilitation Gazette's 3rd International Polio and Independent Living Conference, May 10-12, 1985, St. Louis, edited by Gini Laurie and Judy Raymond. Pub. date: May 1986. \$16 postpaid, \$17 (outside US). Also available from G.I.N.I.

\*\*\*\*\*

Late Effects of Poliomyelitis, edited by Lauro Halstead, M.D. and David Wiechers, M.D. c1984. \$17.95 postpaid. Available from Symposia Foundation, P.O. Box 611857, Miami FL 33161. (305) 891-0658.

\*\*\*\*\*

Proceedings of the Ontario March of Dimes Roosevelt Post-Polio Seminar, June 1, 1985. \$5 Canadian.

Ontario March Dimes Survey, Late Effects of Poliomyelitis, 1985. \$5 Canadian. Available from Ontario March of Dimes, 60 Overlea Blvd., Toronto Ontario M4H 1B6 Canada. (416) 425-0501.

INTERNATIONAL POLIO NETWORK MEMBERSHIP

Membership in the International Polio Network is open to polio survivors, health care professionals, and interested persons.

The Network was formalized under the aegis of Gazette International Networking Institute (G.I.N.I.) during its third international polio conference in May 1985.

Membership (\$5) includes a one-year subscription to Polio Network News, a quarterly bulletin. Members also receive the latest directory of physicians and post-polio support groups in the U.S. and Canada.

NAME \_\_\_\_\_

ADDRESS \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Return this portion with \$5 check payable to: G.I.N.I. 4502 Maryland Ave., St. Louis MO 63108. (314) 361-0475.

**Gazette International Networking Institute**  
4502 Maryland Ave.  
St. Louis, MO 63108 USA.  
Telephone (314) 361-0475  
Address Correction Requested

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

---

WATCH CBS  
SUNDAY MORNING WITH CHARLES KURALT  
FEBRUARY 16, 1986

A ten minute feature on polio survivors, their accomplishments and problems; Gini Laurie, Editor, Rehabilitation Gazette; and the Second International Post-Polio Conference, May 6-8, 1983, St. Louis, Missouri, sponsored by Rehabilitation Gazette.

First aired in June 1983, CBS producers will re-run this feature. Stay tuned!

(There may be a last minute program change. Check with your local CBS station.)

---

1986 CALENDAR

March 14. Pennsylvania and New Jersey Bi-State Polio Conference. Philadelphia Airport Hilton. Contact: Pennsylvania Easter Seal Society, P.O.Box 497, Middletown, PA 17057 (717) 939-7801 or New Jersey Easter Seal Society, P.O.Box 155, Milltown, New Jersey 08850.

May 1-2. Post-Polio Conference. Houston Intercontinental Hotel. Contact: Marge Gordon, Dept. of Education, T.I.R.R., 1333 Moursund St., Houston, TX 77030 (713) 797-5944.

May 7. Post-Polio Update. Smithtown Sheraton Hotel (Hauppauge). Contact: Phyllis Linker, Easter Seal Society, 734 Walt Whitman Rd., Melville, NY 11747 (516) 421-2200.

1987 CALENDAR

June 5-7. Rehabilitation Gazette's Fourth International Polio and Independent Living Conference. Sheraton St. Louis. Contact: Gazette International Networking Institute, 4502 Maryland Ave., St. Louis, MO 63108. (314) 361-0475.

---

Deadline for Spring 1986: March 7, 1986. Send news items to:  
Robert Gorski, 1111 20th St., N.W., Room 600, Washington DC 20036 OR  
Deborah Brewer, 8905 Oneida Lane, Bethesda MD 20817.