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POLIO NETWORK NEWS

Summer 1986

Vol.2 No.3.

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:

Gini Laurie
Judith Raymond

THANKS to Donald Milardo of Middletown, Connecticut for our new mast-head.

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DEADLINE for Fall 1986
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RUSSIAN POLIO SURVIVOR NEEDS LETTERS OF SUPPORT FROM U.S.A.

For eight years, Russian polio survivor Tamara Tretyakova, 39, and her husband, Simon Levin, 35, have been trying to secure an exit visa from Soviet authorities for her and their son Mark, 8, to join Levin in Deerfield, Illinois.

Tretyakova has been disabled by polio since she was two years old. In recent years, her right leg, which is shorter than her left, has become increasingly weaker.

In 1978, Levin, an engineer, then a Soviet citizen, emigrated to the United States

while Tretyakova remained in Moscow hoping to join her husband. Meanwhile, he became a U.S. citizen in 1983.

Both Tretyakova and Levin have entreated the Soviet authorities for her and their son's release, and she has gone on a hunger strike to call attention to her plight. "All these years," says Levin, "I worked hard to bring to the end this tragic situation."

When Levin saw Charles Kuralt's Sunday Morning Show about Gini Laurie's work with polio and the shots of a conference room full of polio survivors and polio physicians, he determined to seek their help in asking for a "special decision" to allow his wife and son to live as a family in the U.S.

"This is a heartwarming opportunity," says Laurie, "for every member of the International Polio Network, their families and friends, to help a polio survivor and her son emigrate to the U.S. to be a family together and to get treatment for the late effects of polio."



Tamara Tretyakova and Mark.

"Each of us," says Laurie, "just by writing a brief letter, can influence the decision to release Tretyakova and her son by letting the U.S.S.R. know that individuals throughout the U.S. care deeply about family bonds and human rights."

"Let's flood the Kremlin with mail from polio survivors all across the U.S. and Canada. Let's tell our local newspapers and radio and TV stations about our campaign to reunite a Russian polio survivor with her family in the U.S."

HELP TAMARA TRETYAKOVA

Send your original letter to:
Mikhail Gorbachev
General Secretary
The Kremlin
Moscow 103009
U.S.S.R.

(Airmail to U.S.S.R. = 44¢
postage per half ounce.)

Send copies of your letter to:
President Ronald Reagan
The White House
1600 Pennsylvania Ave., N.W.
Washington, DC 20500

Ambassador Yuri V. Dubinin
Soviet Embassy
1125 16th St., N.W.
Washington DC 20036

✓ Armand Hammer, M.D., Chairman
Occidental Petroleum
10889 Wilshire Blvd., Suite 1600
Los Angeles, CA 90024

✓ Tretyakova Tamara
Seslavinskay St. 20, Apt. 28
Moscow 121096
U.S.S.R.

International Polio Network
4502 Maryland Ave.
St. Louis, MO 63108

**POLIO IMMUNIZATION VIDEOTAPE
FROM ROTARY INTERNATIONAL**

"The Polioplus Story," a fifteen minute videotape, describes Rotary International's pledge to promote and assist polio immunization of all children in developing nations. Rotary is working with WHO's Expanded Programs on Immunization and with UNICEF.

The Rotary Foundation of Rotary International has allocated \$23.7 million for accelerated immunization efforts in 33 countries to protect more than 150 million children, and provides up to five consecutive years' polio vaccine for approved national or regional immunization programs.

"The Polioplus Story" is an excellent, poignant, and thoughtful piece dramatizing the fact that polio still is a threat. The video is available in 1/2 inch VHS or Beta format for \$25.00 from ~~Audio-Visual Dept.~~, Rotary International, 1600 Ridge Ave., Evanston, IL 60201. *Jack Giles, Public Relations*

**HALSTEAD LEAVES T.I.R.R. FOR
NATIONAL REHABILITATION HOSPITAL;
CASHMAN GOES TO MONTREAL**

✓ Lauro Halstead, M.D., joined the staff of the National Rehabilitation Hospital in Washington, D.C., in July. He will be succeeded at T.I.R.R. by Dr. William Lloyd.

✓ Neil Cashman, M.D., formerly of the post-polio clinic at the University of Chicago Medical Center, is now at the Montreal Neurological Institute. Dr. Raymond Roos succeeds Dr. Cashman. (See Post-Polio Directory Summer Supplement for new addresses.)

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.

THE ORTHOTIC DILEMMA
by Laura K. Smith, P.T., Ph.D.

While there have been extraordinary advances over the past 30 years in the field of brace-making (now called orthotics), these changes have not always been of help to polio survivors who are unable to obtain satisfactory repair or replacement of their braces, corsets, or crutches. Complaints are heard of arrogance, inattention to needs, lack of understanding of problems, changes that decrease function, absence of resources, and high costs.

Part of the problem is that there are few practicing orthotists, physical therapists, or physicians who know of the unique problems and abilities of polio survivors. The number of universities offering orthotic programs has decreased. With the emphasis now on plastic materials, the knowledge and craftsmanship used in fitting, leatherwork, and fabrication of corsets is scarce. Some of the successful braces used for polio survivors are unknown.

Older braces were made of a special orthopedic steel with hand-forged joints. The uprights could be bent close to the joints and, thus contoured, closely fit the leg. This steel was said "to last forever," and is still in use. The newer brace uprights are made of aluminum and usually have casted joints. The uprights cannot be bent as close to the joints and the braces seem bulkier. The weight factor for the two types is similar for equivalent mechanical purposes as it is when plastic cuffs are used and the weight of the shoe is included.

The major orthotic problem, however, is the extraordinary expectation for the appliances in substituting for weak muscles. The appliance must be designed to meet the unique mechanical needs of each person. There are no two polio sur-

vivors with exactly the same muscle involvement.

To be useful, the brace must prevent pain, substitute for weak muscles, increase ability to stand and walk, increase safety, and decrease energy expenditure. At the same time, the appliance should be comfortable, easily applied and used, durable, adjustable, cosmetically acceptable, and cost-effective.

Other individual variables requiring consideration in design and fabrication are weight, height, age, occupation, activity level, environmental conditions, and other physical or medical problems. Trade-offs and compromises are required since every material, joint, or upright has advantages and disadvantages for different purposes.

Plastics brought a new dimension to orthotics with stated advantages as being modern, lightweight, interchangeable with shoes, more cosmetically acceptable, and providing total contact. For some people with singular problems, these advantages provided improved function. But, as with many new products, plastics have often been promoted for everyone, sometimes with little consideration of the needs of the individual or of the disadvantages of plastics.

Polio survivors who still have the old long-leg braces should treasure them and attempt to have them refurbished if possible. Frequently, the posterior thigh cuff has been lowered which causes increased pressure and sores on the back of the thigh and at the knee.

Those who need short-leg braces may be helped by shoe modifications such as boots with an elevated heel, a heel counter (on the principle of the Swedish clog), or "piano-wire splints" which were successful for drop foot.

Some of the new sports braces can be modified to provide knee or

ankle control and stability for specific post-polio problems. New orthotic applications can benefit polio survivors, but the orthoses should not be applied just because they are new. The appliance should address all of the individual's needs and provide improved or at least equal function.

✓ Address: T.I.R.R., 1333 Moursund, Houston, TX 77030.

SHOE EXCHANGE

The One Shoe Crew is a new shoe referral service, started by Georgia Hehr, R.N. Shoe seekers send in their names, addresses, phone numbers and shoe sizes. Hehr then matches shoe sizes with potential shoe partners. The partners are responsible for agreeing to share expenses and shoes.

✓ To register for this free service, write The One Shoe Crew, 86 Clavela Ave., Sacramento, CA 95828.

ACUPUNCTURE

Edith Davis, polio survivor and acupuncturist, is researching the treatment of the late effects of polio. She has had encouraging results in treating herself, and is collecting experiences and information about "the effectiveness and potential value of acupuncture in arresting or reversing physical deterioration."

✓ Polio survivors who have experienced acupuncture treatment (good or bad) can write Edith Davis, 4421 Fourth Ave. S., Minneapolis, MN 55409.

SWIMMING PROGRAMS

Mt. Diablo Rehabilitation Center in Pleasant Hill, California holds on-going pool classes in their 96° indoor pool for polio survivors. A registered P.T. evaluates and designs individual pool programs. Classes are supervised by Marilyn Crow, R.P.T., Physical Therapy Supervisor, and held in cooperation with Dr. Stan Yarnell's polio clinic in San Francisco and Herrick Hospital's clinic in Berkeley.

✓ Address: 490 Golf Club Rd., Pleasant Hill, CA 94523.

The Post-Polio Resource Group of Southeastern Wisconsin holds a swimming program at the West Suburban YMCA in Wauwatosa. A special water movement exercise program is available to polio survivors in the 88° pool.

✓ Address: Paulette Auclair, Curative Rehabilitation Center, 1000 N. 92nd, Wauwatosa, WI 53226.

POST-POLIO BIBLIOGRAPHY

Additional articles on post-polio to add to the library include:

"Case Studies: Orthotic Management of the Adult Post-Polio Patient" by D. Clark, J. Perry, and T. Lunsford. Orthotics and Prosthetics, Spring, 1986, Vol. 40, #1. Pages 43-50.

"Post-Polio Sequelae: Physiological and Psychological Overview" by Nancy Frick and Richard Bruno, Ph.D. Rehabilitation Literature, May-June, 1986, Vol. 47, No.5-6. Pages 106-111.

"Post-Polio Syndrome: The Battle With an Old Foe Resumes" by Karen Holman, M.D. Postgraduate Medicine, June, 1986, Vol.79., No. 8, Pages 44-53.

POST-POLIO RESEARCH

Research in post-polio is increasing. The National Easter Seal Society and the March of Dimes Birth Defects Foundation recently awarded four \$25,000 one-year grants, and the National Institute of Handicapped Research (NIHR) will announce its grant awards in September. Other research is being conducted in Canada, Minnesota, and Michigan.

✓ National Easter Seal Society awarded a grant to James Agre, M.D., Ph.D., to study the extent to which polio survivors experience weakness in muscles. Address: Dept. of Rehabilitation Medicine, U. of Wisconsin-Madison, E3/350 Clinical Science Center, 600 Highland Ave., Madison, WI 53792.

✓ March of Dimes Birth Defects Foundation awarded Rubin Feldman, M.D., F.R.C.P., a grant to study the use of non-fatiguing strengthening exercises in post-polio syndrome.

✓ Address: Dept. of Physical Medicine & Rehabilitation, University of Alberta Hospitals, 8440-112 St., Room 1713, Edmonton, Alberta T6G 2B7, Canada.

Another March of Dimes grant went to Ronald LaPorte, Ph.D., for a morbidity and mortality follow-up of 1,000 post-polio patients in Allegheny County.

✓ Address: Dept. of Epidemiology, University of Pittsburgh, 130 DeSoto St., Pittsburgh, PA 15261.

✓ March of Dimes also awarded a grant to Raymond Roos, M.D., for viral and immune studies in post-polio.

✓ Address: Dept. of Neurology, The University of Chicago, 5801 S. Ellis, Chicago, IL 60637.

○ In Hamilton, Ontario, Dr. Alan McComas is studying muscle weakness in polio survivors by applying a weak electrical stimuli to a nerve

and then recording the muscle responses on an oscillograph screen. The technique is non-invasive and not painful. Dr. McComas is working with the Ontario March of Dimes, but would welcome volunteers from upper New York State. Address: McMaster University, Dept. of Medicine, Div. of Neurology, Hamilton, Ontario L8N 3Z5, Canada.

✓ Richard Owen, M.D., Sister Kenny Institute, is identifying polio survivors who were treated at Sister Kenny during the epidemic year 1952 (June 30, 1952 - July 1, 1953) to determine physical changes in polio survivors. The group of polio survivors will be compared with a control group of persons of similar ages and activity levels who did not have polio.

Address: Sister Kenny Institute, 800 E. 28th St., Minneapolis, MN 55407.

✓ Kenny Michigan Rehabilitation Foundation provided seed money in May for a one-year grant to establish The Post-Polio Research and Training Program, directed by Frederick Maynard, M.D., at the University of Michigan Hospitals.

Coordinated by Sunny Roller, M.A., polio survivor, the program's goals encompass planning and presenting several out-of-state medical workshops on post-polio, enlisting subjects for post-polio research projects, and surveying the post-polio population for unmet needs to promote problem solving for polio survivors at the local level.

✓ Address: University of Michigan Hospitals, NI-2A09-0491, 300 N. Ingalls Bldg., Ann Arbor, MI 48109.

SOCIOLOGICAL STUDIES OF POLIO

The social history of polio is the dominant theme of the research of several scholars, with interesting variations.

Carrie Kaufmann, Ph.D., has undertaken a social history of the polio epidemics and their aftereffects in Pittsburgh, 1940-1985.

✓ Address: 1451 Barnsdale, #1L, Pittsburgh, Pa 15217.

Marilyn Phillips, Ph.D., needs to contact former poster children who are interested in being interviewed for an oral history project on former poster children.

✓ Address: 1140 Martin Pl., Ann Arbor, MI 48104.

A doctoral dissertation by Barbara Pike will focus on the psychological and social aftermath of the polio experience. Barbara will be interviewing polio survivors and distributing questionnaires, and welcomes volunteers.

✓ Address: 3448 Brookline Ave., Cincinnati, OH 45220.

Jane Smith, Ph.D., is working on a book to be published by Atheneum in 1988 on the history of the introduction of the Salk vaccine as a social event. Smith is an associate at the Center for Urban Affairs and Policy Research at Northwestern University in Evanston.

✓ Address: 811 Lincoln, Evanston, IL 60201.

All of the scholars are polio survivors with the exception of Smith who was part of a test group for the Salk vaccine.

PSYCHOTHERAPY & POLIO SURVIVORS

The therapists who led the psychotherapy group for post-polios in Lansing (see Polio Network News, Spring, 1986) have agreed to write up their findings. For more information, write Charlene Bozarth,

✓ 4815 Arapaho, Okemos MI 48864.

VENTILATOR EQUIPMENT AVAILABLE FROM LIFECARE

✓ Dave Tolle, R.R.T., District Manager for LIFECARE in Los Angeles, has written a clear statement of the relationship between LIFECARE and the March of Dimes on providing in-home equipment to polio survivors. The following is reprinted from Polio Survivors Newsletter, May-June, 1986, Polio Survivors Association, Richard Daggett, President, 12720 La Reina Ave., Downey, CA 90242.

"Many post-polio individuals are totally funded by both a primary and secondary funding source, such as Medicare and supplemental Blue Cross. Medi-Cal (Medicaid) alone or with Medicare qualifies as totally funded. (Check your insurance policy for coverage benefits.) A totally funded post-polio requires no additional support from the March of Dimes.

"For the post-polio with only partial funding (as with Medicare only or 80% insurance coverage), the March of Dimes will act as the co-funding source. In-home ventilators can be obtained only from LIFECARE. The respiratory equipment availed the partially funded post-polio through LIFECARE includes all old and all new types of equipment.

"For the post-polio with absolutely no funding, the March of Dimes will provide in-home ventilators through LIFECARE of only the vintage types. While these devices may be of older design, many are not considered obsolete. LIFECARE's ability to supply and maintain this equipment is not strained or otherwise imperiled.

"In 1986 LIFECARE accepted a commitment to polio survivors that remains solid. While the nature of this March of Dimes support may not be ideal, it is much better than nothing at all."

✓ Address: LIFECARE, 655 Aspen Ridge Dr., Lafayette, CO 80026.

NEW POLIO PUBLICATIONS FROM G.I.N.I.

Proceedings, G.I.N.I.'s 1985 Polio Conference.

\$16 in U.S. & Canada. \$18 overseas. Postpaid.
Available September 1986.

\$ _____

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\$5 in U.S. & Canada. \$7 overseas. Postpaid.
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Rehabilitation Gazette, Volume 27, No. 1, 1986.

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G.I.N.I. maintains a calendar of polio seminars, workshops, conferences, etc. If you are planning any of the above, please check the date with Judith Raymond, 314/ 361-0475, or send information to G.I.N.I., 4502 Maryland Ave., St. Louis, MO 63108.

CALENDAR 1986

- ✓ September 4. The Late Effects of Polio. Atlanta, Georgia. Contact: Webster Cash, 19 Sycamore Square, Decatur, GA 30030. 404/ 522-8980.
- ✓ September 13. Post-Polio Conference. Pine Tree Camp for Handicapped Children, Rome, Maine. Contact: Dorothy Smith, Maine Post-Polio Support Group, 188 Pride St., Westbrook, ME 04092. 207/ 797-5695.
- ✓ September 16-17. Post-Polio Management: A Community Empowerment Workshop for Health Care Professionals and Polio Survivors. St. Luke's Hospital, Saginaw, Michigan. Contact: Sunny Roller, Post-Polio Research & Training Program, University of Michigan Hospitals, Dept. of PM & R, NI-2A09-0491, 300 N. Ingalls Bldg., Ann Arbor, MI 48109. 313/ 763-4485.
- ✓ September 27. Crossing New Bridges: A Conference for Polio Survivors and Their Families. Medical College of Wisconsin, Wauwatosa, Wisconsin. Contact: Paulette Auclair, Curative Rehabilitation Center, 1000 N. 92nd, Wauwatosa, WI 53226. 414/259-1414, ext. 292.
- ✓ October 11. Living With Post-Polio Today. Marriott Hotel, Dayton, Ohio. Contact: Connie Johnson, P.U.R.E., 5301 Roxford, Dayton, OH 45432. 513/253-9866.
- ✓ October 16. The Post-Polio Puzzle. Westborough Plaza, Westborough, Massachusetts. Contact: Barbara Harrelson, Massachusetts Easter Seal Society, 484 Main St., Worcester, MA 01608. 617/ 757-2756.
- October 31-November 1. Post-Polio Conference. (October 31: Physician Education Day - physicians and health professionals ONLY. November 1: Polio Survivors.) Pooksville Marriott, Bethesda, Maryland. Contact: Cameron Janish, Post-Polio League for Information & Outreach, 4200 Wisconsin Ave., N.W., Suite 106273, Washington, DC 20016. 301/ 963-7199.