IPOILIO NIEIWORK NIEWS

Fall 1986

Vol.2. No.4.

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

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

DEADLINE for Vol. 3, No. 1, 1987: 1 February. RUSSIAN POLIO SURVIVOR GRANTED EXIT VISA THANKS TO POLIO NETWORK



Simon Levin, his wife, Tamara Tretyakova, and their son, Mark, arrive in the U.S.

Hundreds of letters written by polio survivors in the U.S. to Russian leader Mikhail Gorbachev were responsible in large part for the granting of an exit visa to Russian polio survivor Tamara Tretyakova. Tretyakova and her eight year old son Mark were reunited with their husband and father, Simon Levin, of Deerfield, Illinois, in Vienna on October 8.

In the Summer 1986 issue of <u>Polio Network</u> <u>News</u>, Gini Laurie asked <u>PNN</u> readers to write letters to Gorbachev, with copies to President Ronald Reagan and Dr. Armand Hammer, urging an exit visa for Tretyakova on humanitarian grounds.

After the appeal in the <u>PNN</u>, polio survivors responded with a flood of mail. The timing of the letter-writing campaign was auspicious for it coincided with the release of U.S. reporter Nicholas Daniloff and the pre-summit posturing.

Shortly after Simon Levin and Tamara and Mark arrived home in the U.S., Levin called Laurie to express his thanks for the efforts of the International Polio Network.

"The heartwarming action on the part of polio survivors is an indication of their concern for human rights and independence," states Laurie.

LETTERS TO THE EDITOR

Feldenkrais Method

"I am writing to see whether there are any ongoing studies of the Feldenkrais Method in relation to post-polio.

"I have derived significant benefits from the Feldenkrais Method, and would like others with post-polio to be aware of the technique."

> Marlys Anderson 2401 W. Southern Tempe, AZ 85282

ED: For more information, consult a physical therapist and/or The Feldenkrais Guild, P.O. Box 11145, San Francisco, CA 94101. 415/550-8708.

New Zealand Support Group

"I have established a small support group of polio survivors throughout New Zealand, and currently watch your publications with great interest.

"I feel it would be highly desirous to attend your postpolio conference. It is my hope to bring a party of 16.

"The interest in postpolio is gaining momentum in New Zealand."

> Phillipa Morrison 2/6 Sanders Ave. Napier, New Zealand

Send your "Letters to the Editors" to International Polio Network (IPN), 4502 Maryland Ave., St. Louis, MO 63108. Please sign and provide your complete address. Deadline for the next issue is 1 February 1987.

SOCIAL SECURITY DISABILITY BENEFITS FOR POLIO SURVIVORS

Forthcoming action from the Social Security Administration (SSA) should make it easier for polio survivors to apply for and receive Social Security Disability Benefits.

On October 30, representatives from SSA met with Marge Torre of the Philadelphia Polio Survivors Association and Gini Laurie and Judith Raymond of the International Polio Network. SSA officials came away convinced that the guidelines for the medical listing for polio were not adequate to obtain a true picture of the "residual functional capacity" of polio survivors. They agreed to issue revisions to make postpolio clearer to state agency adjudicators by the first of the year. (Polio Network News, Vol. 3, No. 1, 1987, will contain more details.)

If you are preparing to file for Social Security Disability Benefits, be prepared with good medical documentation. If possible, obtain your old hospital records. Present a record of when work became limiting, when you became unable to work a full day without a rest period in the morning or afternoon or both, or when you became unable to go from point A to point B without pain or fatigue, etc. You must put some measurement on your inability to work in the way you have in the past.

If you are turned down, an appeal is possible. The steps in the appeal process are welloutlined in a booklet available for \$1 from the International Polio Network (IPN), 4502 Maryland Ave., St. Louis, MO 63108. 314/361-0475.

CUSTOM-MADE HOKE CORSETS BY POLIO SURVIVOR SANDY GOLDSTEIN

Sandy Goldstein, a polio survivor, is an independent corsetiere specializing in custommade Hoke lumbosacral and dorsolumbar support (corset-life back supports).

Sandy designs a pattern from a client's measurements, and then constructs the corset or back support from a durable fabric. Flex or stainless stays are inserted for support, with either friction buckles or velcro for front closings.

Sandy sews in by hand any padding that is needed and supplies loose pads to be inserted where needed.

Average cost is \$200 which includes measurement, design, fittings, and alterations (for the first two weeks after the client receives the corset). A \$100 deposit is required.

People not in Sandy's area are asked to send her their old corset describing needed changes. If no corset exists, Sandy will send detailed instructions for measurement, make the corset to the fitting stage, send it to the client for a fitting, and then complete the corset.

Sandy's address is: Mark I Enterprises, 11013 White Sands, San Antonio, TX 78233. 512/654-3793.

POST-POLIO DIRECTORY REVISION

The 1987 Post-Polio Directory will be mailed in February with Polio Network News. Send new listings and corrections to GINI, 4502 Maryland Ave., St. Louis, MO 63108 or call 314/361-0475 by January 15, 1987. For information on new listings, call or write GINI.

NEW PAIN TREATMENT MAY HELP POLIO SURVIVORS

It's called Trigger Point Myotherapy, and refers to the hyper-irritable spot within a taut band of muscle that is painful upon compression and which can cause referred pain and tenderness.

Myotherapist Susan Meadows spoke at a fall post-polio conference in Bethesda, Maryland, and discussed the use of this non-invasive treatment with polio survivors.

Trigger Point Myotherapy has successfully relieved pain and restored limited movement associated with sciatica, headaches, bursitis, arthritis, TMJ dysfunction, sprained joints, strained or pulled muscles, tendonitis, menstrual cramps, leg cramps, carpal tunnel syndrome, stiff neck and shoulders, and more.

The treatment does not alter structural or anatomical pathology, but does relieve pain associated with the same.

Treatment variations include: use of local ischemic pressure on trigger points followed by stretch; application of wet heat; application of fluori-methane spray while applying passive stretch to the affected muscles; and in-home maintenance programs of progressive stretch.

The technique is based on 40 years of research conducted by Dr. Janet Travell, former White House physician, and Drs. David Simon and Hans Kraus.

To find a myotherapist in your area, call Susan Meadows, Associated Health Practitioners, 2112 F St., N.W., Suite 102, Washington, D.C., 20037. 202/331-4247.

Advice for People with Polio or Other Neuromuscular Disorders

Augusta Alba, M.D. and Alice Nolan, R.N.

New York University Medical Center, Department of Rehabilitation Medicine, Goldwater Memorial Hospital, Franklin D. Roosevelt Island, New York, NY 10044

If you have had polio or suffer from some other neuromuscular disorder and have weakness of the neck, upper trunk, or shoulders but are not on a respirator, you may want to evaluate your respiratory needs. Such a disorder may be polymyositis, muscular dystrophy, amyotrophic lateral sclerosis, spinal muscle atrophy or spinal cord injury. As you grow older, your respiratory reserves will diminish. A potentially serious problem may develop whereby carbon dioxide is retained and oxygen is decreased in your bloodstream. These changes may be obvious but in most cases they are subtle. You can easily recognize weakness if you cannot pick your head up off the bed, raise your arms above your shoulders, turn over in bed by yourself, come to a sitting position or sit independently without a back support. However, it is difficult to recognize when the muscles of respiration (the muscles and rib cage that expand and contract your lungs) are not working adequately. When these muscles are impaired a restrictive respiratory problem results. This is different from obstructive pulmonary problems or disorders of the airways.

In the course of normal aging, our lungs and chest wall become less elastic. We do not breathe as deeply. Our vital capacity, the biggest breath we can take into our lungs and then push out, decreases by 30 cc per year (1 oz). Our cough is not as vigorous. Aging and a neuromuscular disorder produce more serious changes. These changes are maximized by conditions such as kyphoscoliosis and airway obstruction or chronic bronchitis.

Symptoms which may be associated with failing respiratory reserves are numerous and for the most part nonspecific. This means that other medical problems can cause them as well. However, they do serve to alert you to a possible respiratory problem. These symptoms include feeling more tired or becoming exhausted from ordinary activities, and reducing usual activities because of fatigue. Anxiety, inability to fall asleep, restless sleep, awakening during the night with nightmares and awakening in the morning with headache or slight confusion may occur. Brain functions are altered so depression, inability to concentrate, dizziness, sleepiness during the day and blurring of vision may be present. Vascular symptoms such as peripheral cyanosis or an abnormal sensitivity of the extremities to cold and the tendency to develop high blood pressure or a rapid heart beat may be caused by respiratory insufficiency. Breathlessness during activity including such a simple task as speaking may occur. Your voice may be lower than it had been. The breaths you take when you are awake may be very shallow and even more shallow when you are asleep. This is why early symptoms usually occur in sleep. Tranquilizers and sedatives will further depress your respiration and should not be taken, especially at bedtime or during the night.

For many people, the first changes may be difficulty raising secretions and feeling congested with frequent colds. Difficulty raising secretions leads to a sealing off of lung tissue from the airways (atelectasis), or to infections of the lung tissue (pneumonia). The work of breathing becomes even harder and respiratory failure occurs more rapidly. With respiratory failure, the right side of the heart fails causing generalized edema and protein in the urine.

If you have any of the signs and symptoms described above, you should make an appointment to see your doctor. Your breathing can be evaluated by simple tests. One of these is measuring your vital capacity (the maximum amount of air that can be moved into the lungs and then forcibly exhaled). If your vital capacity is reduced but is still above 50% of a predicted value for your age and sex, it is unlikely that your symptoms are related to your diminished breathing capacity except in three situations: marked obesity, partial obstruction of the throat during the night in sleep, and the presence of an intrinsic lung disease such as an old tuberculosis or emphysema. If your doctor considers it necessary, he will refer you to a pulmonary specialist.

The pulmonary specialist will do screening pulmonary function tests, more comprehensive pulmonary function tests if he finds them necessary, and arterial blood gases. He may not find it necessary for you to have a ventilator, but may wish to follow you on a regular semiannual or annual basis, or to see you immediately if you develop an intercurrent respiratory infection. If he suggests mechanical respiratory support, you need not be alarmed. Such support is an insurance policy for your well-being.

The respirator will help you sigh your lungs (stretching or range of motion). It will help you cough, speak and even regain energy that had to be funneled into the increased work that you expended in breathing prior to the use of the respirator. For the most part, the respirators used today are small portable units that operate on either battery or wall current. They are silent, inconspicuous, and are used with a mouthpiece both day and night, unless the person has weakness of the throat. In selected cases, respirators including the iron lung, rocking bed and chestpiece, which provide the person with an inspiration, are still in use. Some people prefer a special body respirator called the pneumobelt especially when they are sitting. This is an inflatable bladder held against the abdomen in a nonelastic corset and cycled with the portable ventilator which mimics the abdominal muscles. If the mouth and throat are weak, a tracheostomy can be considered and the ventilator is connected to a tracheostomy tube. With appropriate follow-up and mechanical ventilation you will increase your sense of well-being and longevity.

Lane, D.J., et al: Late Onset Respiratory Failure in Patients with Previous Poliomyelitis. Quarterly Journal of Medicine, New Series, XLIII, No. 172, pp 551-568, October, 1974.

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POST-POLIO RESEARCH

National Institute for Handicapped Research (NIHR) grants for post-polio studies were awarded in September to:

Frederick Maynard, M.D., William Waring, M.D. - the measurement of fatigue using EMG. Address: University of Michigan Hospitals, NI-A209-0491, 300 N. Ingalls Bldg., Ann Arbor MI 48109. 313/763-4485.

Jennine Speier, M.D., - aerobic conditioning for muscles. Address: Sister Kenny Institute, 800 E.28th, Minneapolis, MN 55407. 612/874-4457.

Jacquelin Perry, M.D. - fatigue in post-polio muscles. Address: Rancho Los Amigos Medical Center, 7601 E. Imperial Hwy., Downey, CA 90242. 213/922-7177.

NIHR's new acronym is NIDRR for National Institute on Disability, Rehabilitation, and Research. J. Paul Thomas, Ph.D., Director of Medical Programs at NIDRR, welcomes more applications from researchers. Write him at NIDRR, Switzer Bldg., Room 3430, Washington DC 20202.

Gerald Herbison, M.D., and his research associate, Mazher Jaweed, Ph.D., are studying strength in affected and non-affected muscles of polio survivors using "Kin-Com," a computer-operated muscle strength testing machine.

Participants in the study will be seen every three months for a one-year period. For more information contact M. Jaweed, Thomas Jefferson University Hospital, Philadelphia, PA 19107. 215/928-6567.

Arthur Ginsberg, M.D., a neurologist in Seattle is collaborating with Dr. Ed Clark at the University of Washington on a project studying the immune system and post-polio syndrome. Ray Endicott, M.D., a polio survivor, participated in the first study of asymptomatic and symptomatic polio survivors, which found definite abnormalities in the autoimmune system. If the results of a second

study are as dramatic as the first, Dr. Ginsberg will apply for a research grant.

For more information, contact Dr. Ginsberg at 1570 N. 115th St., Suite 2, Seattle, WA 98113. 206/365-9290 or Dr. Endicott at 800 E. Aloha, Seattle, WA 98109. 206/548-4294.

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March 1, 1987 is the deadline for grant applications for postpolio research to the National Easter Seal Society. Request application packets from Rita McGaughey, NESS, 2023 W. Ogden, Chicago, IL 60612.

* * *

March of Dimes Birth Defects Foundation is also accepting applications for post-polio research. Send letters of intent to Samuel Ajl, M.D., at the March of Dimes, 1275 Mamaroneck Ave., White Plains, NY 10605.

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.

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WARM SPRINGS II: CAUSES FOR NEW SYMPTOMS IN POST-POLIOS DEBATED AT SECOND RESEARCH SYMPOSIUM by Frederick M. Maynard, M.D.

The Second Research Symposium on the Late Effects of Poliomyelitis held at Warm Springs, Georgia, September 5-7, 1986, brought together 47 leading medical researchers from seven countries to discuss their current investigations into the clinical features, pathologic causes, and useful treatments for the late effects of polio.

It soon became clear that continued work is needed on defining terminology for patient categories and clinical symptoms, as well as on finding objective measures of neuromuscular function. Debate continued about the exact meaning of the terms Post-Polio Syndrome and Post-Polio Progressive Muscular Atrophy. The five most common symptoms related to the late effects of polio were agreed to be abnormal fatigability, pain, new weakness in muscles previously affected or unaffected by polio, new loss of functional ability, and cold intolerance.

Unfortunately, these symptoms are common in the general population and can be a result of many other medical and psychological disease states. As a result, it is extremely difficult to establish criteria for Post-Polio Syndrome that are objective and that can be uniformly applied by many different clinical observers. On the other hand, Post-Polio Progressive Muscular Atrophy is not always accompanied by atrophy, is not always progressive, and the term still lacks specificity concerning the degree of strength decline. The limitations of manual muscle testing for assessing degree of weakness or changes in strength were agreed to by everyone.

Adding to the confusion over terminology was the conclusion of most investigations that there are not significant or consistent differences on electromyographic (EMG) or muscle biopsy studies between post-polios with and without new symptoms. These studies showed a continuum of abnormalities in nerves and muscles of both groups. This conclusion suggests that it is not really a new disease state that is affecting polio survivors who are developing new symptoms and functional losses. Rather, it suggests that new symptoms come from physiologic (functional) changes in the previously involved nerve cells and muscles, not structural changes. The physiologic abnormalities of nerve and muscle most discussed at the conference were changes in metabolism of nerve and muscle as a result of chronic overuse; immunologic changes, and environmental toxin effects.

Another major point of agreement was the need to measure objectively abnormalities and changes in nerve and muscle function so that treatment interventions can be scientifically assessed with prospective studies. The latest neurophysiologic techniques for objective measurement of nerve and muscle function, including measurements of strength, were discussed, and preliminary results of their use with polio survivors were presented.

G.H. Pezeshkpour, M.D., of the Armed Forces Institute of Pathology, reported complete autopsy studies on seven people with a past history of acute and chronic polio. He found no differences between muscles of newly symptomatic patients and asymptomatic patients. He emphasized the need for a much larger study with (The next issue of <u>Polio Network News</u> will include a protocol by Dr. Pezeshkpour for organ donations among polio survivors to assist with this investigation.)

Several special clinical management problems of polio survivors were discussed. These included management of progressive dysphagia (difficulty swallowing), management of slowly developing respiratory failure and sleep apnea (underventilation at night), pain, and emotional stress.

Two new promising areas of investigation and management into treatment were reported. One explored environmental effects on Post-Polio Syndrome. These include vitamin and mineral deficiencies, exposure to low levels of toxins such as lead and pesticides, and allergens such as pollen, carbon monoxide, and chemical fumes. The concept was that polio survivors have a damaged and fragile nerve and muscle system which will develop symptoms at low levels of exposure to toxins, allergens, and deficiencies.

Investigators from England reported similarities between post-viral syndrome symptoms and Post-Polio Syndrome. A definite improvement of symptoms was experienced by eight of twelve polio survivors who were treated with environmental medicine methods. Another study reported improved strength occurring in the majority of weakened polio muscles in which carefully controlled and slowly progressive strengthening exercise programs were carried out. Results were fairly short-term and modest in degree. They did seem to demonstrate that, under the right circumstances, post-polio muscles can still show some improvement in strength.

The theory of symptoms being caused from chronic overuse was given support by a study from Rancho Los Amigos Medical Center in Downey, California. Dr. Jacquelin Perry reported quantitative electromyographic studies during walking on leg muscles of both symptomatic and asymptomatic post-polios. When electrical activity was looked at in proportion to the maximum force produced on quantitative strength testing, she found that the symptomatic polio survivors were using an extremely high proportion of their maximum muscle strength with each step of walking. Muscles were also being used for abnormally long periods of time during each step. This supports the concept that chronic overuse may well explain much of the muscle pain and fatigue experienced by polio survivors, in addition to the many inflammatory musculoskeletal pain syndromes after acute strains which clearly produce pain. Participants uniformly agreed on the need for further study of the psychological issues which influence pain symptoms.

One of the most useful and exciting aspects of the conference was the cross-fertilization of ideas between clinical and laboratory investigators that occurred. The peaceful wooded retreat environment of Warm Springs allowed the participants to know each other on a personal basis which stimulated lively discussion and exchanges of ideas. All participants agreed that the conference stimulated and advanced their thinking and work on the causes and treatment of the late effects of polio.

Address: University of Michigan Hospitals, NI-2A09-0491, 300 N. Ingalls Bldg., Ann Arbor, MI 48109. 313/763-4485.

Post-Polio Clinic in Toronto

West Park Hospital's post-polio clinic in Toronto, Ontario, opened in November with an interdisciplinary team including Dr. William Franks, director of the Neurological Rehabilitation Program, Dr. Roger Goldstein, director of Respiratory Medicine, an occupational therapist, physiotherapist, and social worker. For information, write Anne Randell, West Park Hospital, 82 Buttonwood Ave., Toronto, Ontario M6M 2J5 Canada, or call 416/243-3679.

Additional post-polio clinics are scheduled to open in Windsor, Ontario, and in Victoria, British Columbia.

Networking in Ontario and British Columbia

The Post-Polio Awareness and Support Society of British Columbia has 24 area groups, a physician's registry, and over 1,300 polio survivors listed with the British Columbia Health Surveillance Registry. Write Rheta Davidson, 4291 Oakfield Crescent, Victoria, B.C. V8X 4W4 Canada. 604/479-7874.

The Ontario March of Dimes has helped organize 13 support groups in Ontario province, and sponsored a Polio Information Day in September. <u>The Advocate</u>, a bi-monthly newspaper published by the Ontario March of Dimes, features an entire post-polio section. Shirley Teolis coordinates the program at Ontario March of Dimes, 60 Overlea Blvd., Toronto, Ontario M4H 1B6 Canada. 416/425-5001.

Polio Handbook in Swedish

In Swedish, the title is <u>Handbok om Polio: att leva</u> <u>lange med en polioskada</u>. The translation was done by respiratory polio survivor Adolf Ratzka, Ph.D., and the Swedish Anti-Polio Society.

Dr. Ratzka organized a major polio conference in Stockholm in 1984, which was followed by regional conferences. He recently returned from a polio conference in Norway.

Translations of the <u>Handbook</u> into French, Italian, German, and Chinese are in progress.

Polio Outbreak in South Africa

Kathy Jagoe, C5-6 quad, writes of a polio outbreak in July 1986 in Alexandra, near Johannesburg:

"... it is of great concern every time we hear of another outbreak.... another recently in Alexandra...still with a bucket system for toilets, tiny, overcrowded houses, and outside street taps."

Dr. Tim Wilson, head of the Alexandra Health Centre, listed poor sanitation, housing, stormwater drainage, and infrequent refuse removal as the causes. Immunization operations were hampered by the emergency regulations in South Africa.

In July, 195, the World Health Organization (WHO) reported 2,058 cases in Africa. WHO official Ko Keja, M.D., DrPH, cautions that the reported figures represent only 5% to 10% of <u>all</u> cases.¹

¹Worldwide assault on poliomyelitis gathering support, garnering results by Chris Raymond, Ph.D., Journal of the American <u>Medical Association</u>, March 28, Vol.255, No.12, pages 1541-1546.

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1987 NATIONAL HEALTH INTERVIEW SURVEY INCLUDES POLIO QUESTIONS

The National Center for Health Statistics (NCHS) collects and analyzes data on major health issues through its Division of Health Interview Statistics.

The 1987 National Health Interview Survey (NHIS) will include three questions about polio. Survey results should yield a valid, current statistic on the number of polio survivors in the U.S. which will be invaluable for post-polio clinicians and researchers.

A follow-up study to investigate the prevalence of polio's late effects <u>may</u> be targeted for 1989.

The survey, a cross-sectional household interview survey, will sample and interview an estimated 50,000 households continuously throughout 1987.

For more information contact Peggy Barker, NCHS, 3700 East-West Hwy., Hyattsville, MD 20782. 301/436-7093.

POST-POLIO BIBLIOGRAPHY

Recently published articles:

"Polio Revisited: Survivors in the '80s" by Ann Hueter, R.P.T., Physical Therapy Forum, July 23, 1986, Vol. V, No. 30. Pages 1-4.

"Postpolio Deaths Stir Debate" by Paul Cotton. <u>Medical World News</u>, August 11, 1986. Pages 20-21.

"Polio's Painful Legacy" by Joy Horowitz. Funk & Wagnall's New Encyclopedia, 1987 Science Yearbook. Pages 24-247. (This is an expanded version of Horowitz's article in The New York Times Magazine, July 7, 1985.)

FLU SHOTS RECOMMENDED FOR POLIO SURVIVORS

Polio survivors with respiratory insufficiency or over age 65 should receive the standard flu vaccine, advise Drs. Augusta Alba and D. Armin Fischer, both well known post-polio experts.

A new flu vaccine to combat the Taiwan flu is also recommended. Polio survivors without respiratory complications should check with their physicians about receiving the flu shots.

REGIONAL POLIO CONFERENCES: NETWORKING IN ACTION

Polio support groups organized successful, informative, and creative conferences in eight cities between August and mid-November. International Polio Network Coordinators Judith Raymond and/or Gini Laurie attended each conference, speaking at seven of them. They were impressed by the information exchange and networking.

Each conference had its own style, but all contributed to the spread of knowledge about the treatment, management, and psychology of polio's late effects.

The groups are identifying physicians and physical therapists who are willing to listen and learn about post-polio; they are locating good brace-makers and van-conversion shops; they are evaluating electric scooters and other adaptive equipment all within their communities.

The locations and dates of the conferences were: Greenville, SC August 8-9, Atlanta, GA September 4, Milwaukee, WI September 27, Dayton, OH October 11, Boston, MA October 16, Memphis, TN October 25.

Bethesda, MD

Dallas, TX

October 25, Oct.31-Nov.1, November 8.

9

JULIANA SAWYER STOLLE, AN AMERICAN POLIO SURVIVOR LIVING IN LUBECK, WEST GERMANY

Excerpts from a letter responding to questions about Juliana's polio days at Children's Hospital in Columbus, Ohio in 1955 -

"After reading your latest literature, it seems as if my health is following the normal path. I have been running through brick walls for the past 30 years, and am finding now that there are walls I have to go around.*

"...you bring forth many memories, and you would be surprised that all are very pleasant ones. It may be strange to say that my almost-year at Children's Hospital in Columbus was one of the happiest I spent and surely the most forming. In a matter of months, I was turned from a superficial teenager to a compassionate adult, with insight and strength, qualities I may not otherwise have had, and that have surely enriched my life.

"In September, 1955, I was an 18-year-old, and curious as to what college would bring. After just two weeks, barely beyond freshman week, I came down with polio. After a month in isolation at University Hospital (in Columbus), I was transferred to Children's Hospital, then a central therapy hospital for polio with patients from all over Ohio.

"Our doctors were young, handsome, and devoted way beyond duty. We were cared for by Drs. Oliver, Johnson, Burke, and Walker. Dr. Burke loaned one of the physical therapists his car with hand controls so that I could learn to drive in the last weeks of hospital stay. We were surrounded by optimists: if we worked hard enough, all would be well.

"Perhaps all this sounds too good to be true, but it was thus. On the other hand, we were young, completely untouched by life and the big bad world. I read in the <u>Gazette</u> an article about adjustment being harder the second time around. When the second time comes, one has responsibilities, a husband, children, and one isn't as innocent about expectations of the future.

"I am sure I would never have been able to adjust to living in a foreign country without my polio experience. I met my husband on a trip to Europe the summer of my junior year. I talked my parents into letting me spend a year in a German university, and returned a year later, engaged. My husband-to-be came over ten days before the wedding. When I look back, what chances we take! It has been a very, very happy marriage.

"Perhaps you have in your records the addresses of Julie Cochran or Sarah Core (maiden names), both roommates at Children's Hospital. I lost touch with them, and would like to find them again."

> Juliana Sawyer Stolle Kaninchenbergweg 63 2400 Lubeck Federal Republic of Germany

*Juliana wears a long leg brace on her right leg and uses crutches. She is now having post-polio problems with her shoulders, hands, and arms.

SPECIAL CONFERENCE RATE FOR GINI MEMBERS

Registration fees for GINI's 1987 international polio conference (as listed on the next page) reflect a discount for GINI members.

GINI membership dues must be paid or renewed before May 1, 1987, in order to qualify for the conference discount. (See GINI membership below.)

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DO YOU HAVE	ALL OF THESE PO	LIO PUBLICATIONS?	???
ARE	YOU A GINI MEMB	ER???	
Handbook on the Late Eff	ects of Poliomy	elitis	
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Proceedings, GINI's 1983 Conference. c1984. \$16 p	International ostpaid.	Polio	\$
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Help locate polio survivors! They may be experiencing new health problems related to polio. The Polio Sleuth originated with the Michigan Polio Network, and is now being adopted by many polio support groups to locate polio survivors.

The Polio Sleuth has been used on posters placed in stores, libraries, doctor's offices, hospitals, clinics, etc., with good results.

Thank you, Michigan, for this idea for a nationwide polio survivors' search campaign.

PLAN NOW TO ATTEND GINI'S FOURTH INTERNATIONAL POLIO CONFERENCE

PRELIMINARY CONFERENCE INFORMATION

<u>Rehait</u> Annua

	GINI Members	Nonmembers
FULL REGISTRATION: Nonprofessionals/students Health & rehabilitation professionals	· · · · · · · · · · · · · · · · · · ·	\$75 ds.dag \$165
SINGLE DAY REGISTRATION: Thursday/Friday/Saturday/Sunday		

Nonprofessionals/students	\$15	\$25
Health & rehabilitation professionals	\$40	\$55

HOTEL: Sheraton St. Louis conference rates are approximately \$70⁻²⁵⁰ (including tax) per night, single or double occupancy. If possible, plan to share a room to save on expenses.

MEALS: The conference meal packet is approximately \$100 for Thursday lunch and dinner, Friday lunch and dinner, Saturday lunch and banquet, and Sunday lunch. Free continental breakfasts will be offered on Saturday and Sunday mornings.

AIR TRAVEL: Make reservations 30 days in advance for large savings.

Complete conference registration packets will be mailed in late January 1987. Write GINI, 4502 Maryland Ave., St. Louis, MO 63108 USA.