

# POLIO NETWORK NEWS

Summer 1989 ■ Vol. 5, No. 3

## International Polio Network

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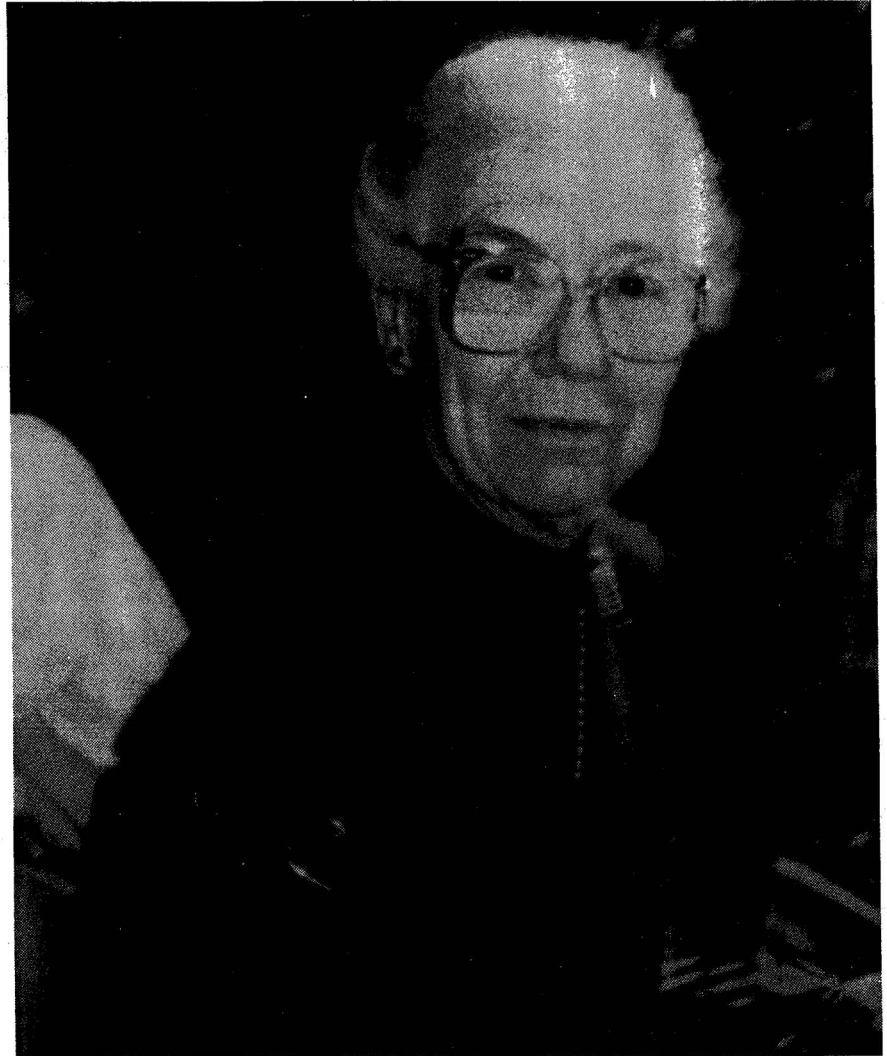
Polio Network News is an international newsletter for polio survivors, support groups, physicians, health professionals, and resource centers, to exchange information, encourage research, and promote networking among the post-polio community.

**Annual Membership:**  
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## *Gini Laurie*

June 10, 1913 – June 28, 1989

Virginia Grace Wilson was born June 10, 1913 in St. Louis as a replacement child for two sisters, Virginia and Grace, who died of polio during an early epidemic. She and Joseph Scott Laurie III were married February 26, 1943.

Gini, as she was known throughout the world, worked as a volunteer in the 1950s at Toomey Respiratory Polio Center in Cleveland.

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# Gini Laurie

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Vera Overholt, polio survivor from Ohio, remembers, "She would always bring a sunny smile and some story about her cats. Nothing was ever too much trouble for Gini! She gave her life to us. Needless to say, we loved her."

During their months and years in the hospital, polio survivors understandably developed close friendships. When their rehabilitation was completed, they went home to family leaving their polio friends behind. But Gini was always there. It was inevitable that Gini became the contact person for "whatever happened to..."

This initial Christmas card list expanded into a mimeographed publication, Toomey j Gazette, which was written by her friends from Toomey for other individuals with a disability. The modest publication evolved into an international journal written primarily by people with disabilities - the Rehabilitation Gazette.

Celebrating its 30th anniversary in 1988, the Rehabilitation Gazette (Volume 29, Nos. 1 & 2), is a collection of 40 life experiences explaining how they, friends of the Gazette, got "here from there."

Bud Blitzer, long time Gazette friend from California, comments, "Even though the main body of the issue was written by and about us, the issue is unmistakably a tribute to Gini. All of us know how much she contributed toward whatever we accomplished and how much better she helped us feel about ourselves."

Being the "glue that held polio survivors together," Gini was one of the first to recognize the late effects of polio. In 1981, she organized a conference to alert her polio survivor friends and to involve the medical community. Frederick Maynard, M.D., University of Michigan Medical School, recalls,

"Gini was the catalyst. If she had not held that first meeting, it is possible we might still not know about these effects. Eventually, we might have noticed that many post-polio people had problems, I guess. But when?"

Living life to its fullest and believing that all individuals should do likewise, Gini was one of the instigators of the independent living movement. Her personal goal was to reach, to inform, and to dignify persons with individuals worldwide. She authored Housing and Home Services for the Disabled: Guidelines and Experiences in Independent Living which was published in 1977 by Harper & Row. Jim Tuscher, Paraquad, Inc., St. Louis, remarks that "the hospital taught you how to survive, Gini taught you how to live."

In 1985, the Rehabilitation Gazette board formally founded the organization, Gazette International Networking Institute (G.I.N.I.), which today is the umbrella organization for the International Polio Network (1985) and the International Ventilator Users Network (1987).

After 40 years of volunteer work on behalf of individuals with disabilities, Gini died of cancer in her home on June 28, 1989.

A recent quote sums up Gini's philosophy about disability. "Peopleness is the only thing that matters. Disability is unimportant. The basic cause of most problems is a negative attitude. That's more handicapping than disability. And our attitudes are our responsibility. We can change. We can influence others."

Pledging to continue her work, the G.I.N.I. Board of Directors by resolution established The Gini Laurie Endowment which was announced at the Fifth International Polio & Independent Living Conference on June 4, 1989. The resolution of tribute is reprinted on the next page.

# Resolution

*Whereas*, the Gazette International Networking Institute (G.I.N.I.), through its *Rehabilitation Gazette*, has for thirty years been the vital organizational extension of the soul and work of Gini Laurie, its founder and inspiration, and

*Whereas*, Gini Laurie has profoundly affected the lives of nearly everyone who has survived the effects of polio, recently identifying the late effects of polio and thereby helping to extend the lives of thousands, and

*Whereas*, Gini Laurie has generated and, with friends having disabilities of all types, has shaped a movement toward independent living around the world, which has become a living and evolving memorial to her own joyful and independent spirit,

*Now therefore be it resolved* that the Board of Directors of the Gazette International Networking Institute create and establish *The Gini Laurie Endowment*, a capital fund under its auspices, the income from which will be used to support the work of G.I.N.I., including the continued publication of experiential information by and among people with disabilities toward ever richer and independent living with physical disability;

*And be it further resolved* that the Board of Directors will actively seek the increase of the corpus of the fund to a level that will guarantee a vital continuation of Gini Laurie's vigorous lifelong publishing work.

*May 16, 1989*

To contribute to *The Gini Laurie Endowment*,  
send your tax-deductible contribution to  
G.I.N.I., 4502 Maryland Avenue,  
Saint Louis, Missouri, 63108 USA.

# Fifth International Polio & Independent Living Conference

Over 450 polio survivors, health professionals, attendants, families, and friends attended the Fifth International Polio & Independent Living Conference May 31-June 4, 1989 in St. Louis.

Starting with this issue, Polio Network News will include excerpts and summaries of presentations made at the Conference.

Audio and visual tapes were made of most sessions. An order form was printed in the Spring Polio Network News (Vol. 5, No. 2.). Forms are also available from IPN or St. Louis Audio Visual, Inc., 2114 Schuetz Road, St. Louis, MO 63146 (314/993-3388). All orders should be placed directly with St. Louis Audio, Inc.

The 30-page Conference program and the Conference bag are available while the supply lasts. The 11" by 14" by 3" rayon canvas bag has waterproof interior, over the shoulder handles, and full size all-around gusset. It is a natural color with a red logo. Send \$9.50 (includes postage) to IPN, 4502 Maryland Avenue, St. Louis, MO 63108. If you would like to purchase a quantity of bags, contact IPN for rates.

## International Progress Reports: NETWORKING

### TAIWAN

By Rev. Robert J. Ronald, SJ,  
Taipei, Taiwan

Polio was not made a reportable disease until 1955, but not all cases have been recorded. The official medical department statistics show only an average per year of 513 cases in the late 50s, 477

cases in the early 60s, and 8 cases in the decade of the 70s.

Figures show the dramatic effects of the Salk vaccine which was first introduced in 1958. After a few years of mainly urban use, it finally became available everywhere. There was a new epidemic that lasted six months in 1982, hitting mostly those not vaccinated. Since then all children have been immunized.

But the figures do not accurately show the true extent of polio, because it is estimated that there are presently in Taiwan between 70,000 and 120,000 polio survivors.

In 1985 Operation De-Handicap conducted a mail survey that was sent to over 500 polio survivors in the Taipei area. Two hundred and sixty responded.

The median age of onset was about two years old (47% -one year old or less, 16% -two years old, 27% -three years old, and 10% -over three years old, the oldest being 24).

This is very different from what is reported in America, where some surveys show as many as 25% getting polio after the age of 20.

At the time of the survey, the 260 Chinese showed 20% had one arm disabled, 8% had both arms disabled, 48% had one leg disabled, 50% had both legs disabled, 50% had undergone corrective orthopedic surgery, 14% were using a wheelchair, 41% were using crutches, 61% were using braces, 34% reported scoliosis, 50% reported foot, knee and/or hip deformity, and 25% reported one leg shorter than the other.

This is also very different from that of American polio survivors in one major respect. No one on Taiwan, to my knowledge, is using respiratory assistance. Those with respiratory failure probably ended up among the deceased. Another



factor is the fact that bulbar polio hits predominantly those who get polio at a later age. The Taiwan group was relatively young.

In spite of the youth of this Chinese group and the rather short length of time since their onset, 82% were experiencing changes, 39% were walking less, 47% of wheelchair users were using them more, 36% were tiring more easily, 28% complained of new weakness, 20% complained of joint pain, and 14% complained of low back pain.

This data is already four years old and not necessarily representative of all polio survivors. (Operation De-Handicap is conducting a new survey.)

Taiwan does not have formally established polio support groups with registered membership or regular meetings, but there are several organizations which have extensive contacts with polio survivors and which are serving as sources of guidance and dissemination of information.

The most active of these is my own organization, Operation De-Handicap (O.D.H.). In 1985 after my return from the St. Louis meeting, Ignatius Huang, the Executive Manager of O.D.H., prepared an 80-page Polio Handbook in Chinese that was printed by the Rotary Club of Taipei-Tienmou. It received an award for excellence from the government. Four thousand copies were distributed free. People are still asking for it and we are hoping to find new funding to print and distribute a second edition. Operation De-Handicap has sponsored a number of public seminars on post-polio and regularly prints articles of information, suggestions on exercise, and how to deal with the post-polio sequelae in Restoration Magazine, its quarterly publication. Copies of Operation De-Handicap materials have been made available for use in Hong Kong and Singapore.

Also in Taipei, the Ching-Hsin Rehabilitation & Medical Center, the Rehabilitation Center of Veterans General Hospital, Goodwill Industries, Inc., and the Eden Welfare foundation which sponsors vocational and social activities for persons with disabilities, are concerned about the growing number of post-polio problems that are being brought to their attention. In other parts of Taiwan wherever there are groups for persons with orthopedic disabilities, attention is beginning to be focused on post-polio and what should be done about it.

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#### CANADA

By Audrey J. King, Toronto, Canada

Much has happened across our vast country since the first GINI Conference in 1981.

In the Maritime provinces, Newfoundland, PEI, New Brunswick, and Nova Scotia, there are varying degrees of organization. New Brunswick held an inaugural meeting in May 1987. Dr. Shears is seeing polio survivors and conducting research in Halifax, Nova Scotia.

Quebec has seven very active local groups which includes meetings conducted in "polio-speak," a mixture of English and French. A clinic and research, under the auspices of Dr. Neil Cashman, offers support to many.

In Ontario, the March of Dimes has provided administrative assistance and minimal start-up funding to many of the 26 autonomous local support groups. Provincial conferences in 1983 and 1985 have been held, as well as ongoing local and regional meetings. A post-polio assessment clinic at West Park Hospital recently closed after two years due to lack of government support.

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## International Progress Reports:

### NETWORKING (continued from page 5)

As a result of much government lobbying, an outreach respiratory clinic will soon be operational in Manitoba to complement the hydrotherapy program. An emerging issue is the situation of polio survivors living in isolated rural areas.

The Saskatchewan group was organized in late 1988 and a one-day educational seminar is planned for this October.

Alberta now has eight support groups headquartered in Calgary. The more northern Edmonton group is currently joining forces with Calgary. Dr. Feldman continues to run a research clinic in Edmonton and a doctor at Calgary General Hospital is beginning to offer post-polio medical support. Alberta's Royal Canadian Legion, which has continuously supported polio needs since 1952, has been a valuable source of financial support in both regions.

The group in British Columbia now lists 40 support links throughout the province. A Pacific Northwestern Conference is planned for November 2-5, 1989 (see calendar).

With financial support and encouragement from Canada's Department of National Health and Welfare, Canadians from coast to coast were able to attend Canada's first National Post-Polio Conference in Toronto in 1988. A follow-up meeting, again supported by the federal government, will occur later this year in Winnipeg, Manitoba.

Presenting this report was a personal joy for me and a tribute to the "people-power-persistence" of polio survivors and their friends everywhere. Our strength comes from our commitment and from each other, however widely scattered we may be.

## WEST GERMANY

By Gertrud Weiss, Rosenheim, West Germany

### The Situation of the Polio Survivor in West Germany

The term "situation" means the patient's position vis-a-vis therapists and doctors of various specialties, of whom the orthopaedic surgeons feel to be the most competent to make judgement. As to information in medical journals, we are in the earliest embryonic state one can think of. In 1986 and 1987 there were two short news items quoting Dr. Marinos Dalakas and Dr. Neil Cashman from the New England Journal of Medicine and later a half-page summary of both reports. Knowledge and awareness of late effects is near zero.

A minor breakthrough came in 1988 by the convening of the International Conference on the Late Effects of Poliomyelitis and Chronic Underventilation (Munich, April 7-9, 1988) and with the publication of three of my articles, one in a medical newspaper "For Clinic and Practice." Many polio survivors copied the articles and showed them to their doctors but without much response.

A few physicians did become interested. One university professor wanted to inform former students and physiotherapists now working in rehabilitation clinics. However none of that group asked for the literature offered.

Some physiotherapists agreed to inform their former schools but one medical advisor commented, "Not worthwhile." Two others responded more positively. A professor from the Max-Planck-Institute asked for literature because it was "new, very interesting, and important." His brother and a friend had been severely disabled by polio. Personal involvement might be the main impetus for interest in the late effects of polio.

Younger physicians and even orthopaedists are of the opinion that polio is "out." They prefer to deal with the more profitable topics. The majority clings to the old training system of strenuous exercise.

Some family physicians try hard to help. Others say, "You are getting older. You have to live with it." They at least know whether or not a patient is over reacting or malingering.

Sometimes, polio survivors are reproached for over reacting or malingering by inpatient specialists and by government commissioned health officers or insurance agencies. Because of the cost for health insurance, physical applications are rationed. Physicians have to assess the grade of disability for tax reductions and other entitlements for disability retirement and some social services.

The health problems of most polio survivors are mostly approached in typical patterns. Anti-rheumatic drugs, pain-killers, and vitamin B and C are advised. Massages, electrical therapy, and swimming are also recommended but rarely exercises guided by a physiotherapist. Few doctors still prescribe cortisone. One positive aspect is that the awareness for the need for respirators is growing.

The medical community in general got accustomed to the notion that polio survivors did a good job of integrating into society. Physically as well as with their brains, they compensated effectively for functional limitations. Since this has worked for a long time - why shouldn't it continue?

From 1946 to 1962 there were about 54,000 polio cases in West Germany. Seventy (70%) to seventy-seven (77%) per cent were paralytic. From 1962 to 1987 there were 707 cases. Since there are no official

statistics, I calculated these numbers from piecemeal information. Nothing is available before 1946.

As to my knowledge there is not a single research study being done in West Germany. Neither do we have a post-polio clinic. So education of the medical world will have to start from the grassroots.

## **International Progress Reports: RESEARCH**

### RESPIRATORY POLIO SURVIVORS

By D. Armin Fischer, M.D., Rancho Los Amigos, Downey, CA

In late fall of 1988, The Polio Survivors Association in Downey, California, led by President Richard Daggett, circulated questionnaires on swallowing problems (dysphagia) and sleep disordered breathing to its membership of 950.

112 (12%) questionnaires were returned from all across the U.S. and even Canada. However, over half (67 or 60%) of the responses came from California. The earliest onset of the acute polio stage was 1912; the latest onset reported was 1959.

Seventy-six (68%) females answered the questionnaire with the remaining 32% of the questionnaires answered by males. The oldest respondent was 85 years old; the youngest was 37 years old.

At onset, 80% had breathing problems, 56% used a ventilator, and 41% experienced swallowing problems. Currently, 59% are experiencing breathing problems, 36% use a ventilator, and 33% are having swallowing problems.

Sixty-five percent (65%) of those who reported breathing problems at onset also reported breathing problems now. Sixty percent (60%) of those who used a ventilator at on-

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### RESEARCH (continued from page 7)

set reported using a ventilator now. And 59% of those who had swallowing problems at onset are also experiencing swallowing problems now.

Of those who reported sleep disordered breathing problems, 57% reported awakening frequently during the night and 54% reported daytime sleepiness.

Polio survivors start out with diminished respiratory reserve, and, as they age, lose vital capacity at the normal rate of about 1% per year. It would appear, however, that sleep and swallowing problems are more prevalent than previously reported.

Polio survivors with swallowing problems should take care in eating to avoid aspirating. Swallowing clinics are becoming more common (Gaylord Hospital in Connecticut, Johns Hopkins in Baltimore, to name a few), and physical therapists can also provide suggestions for alleviating swallowing difficulties.

Sleep disorders in polio survivors should be confirmed by a sleep study, and appropriate treatment with some form of mechanical ventilation begun.

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### DYSPHAGIA IN POST-POLIO SEQUELAE

By Carl A. Coelho, Ph.D., Gaylord Hospital, Wallingford, CT

#### Purposes of Study

To identify individuals whose symptoms of Post-Polio Sequelae include swallowing difficulty (dysphagia);

To describe the nature of dysphagia;

To identify appropriate noninvasive treatment options for these individuals;

To longitudinally follow these individuals and monitor changes and the impact of treatment.

#### Method

220 questionnaires were mailed to members of two Post-Polio support groups in Connecticut.

109 responses have been received to date (50%).

80 of the 109 (73%) reported having no difficulty with swallowing.

29 of the 109 (27%) reported having occasional or consistent difficulties with swallowing.

Of these 29: 5 did not want to be evaluated, 14 have been evaluated, and 10 will be evaluated in the near future.

#### Evaluation Procedure

1) Clinical swallowing evaluation; 2) Videofluoroscopic swallowing evaluation; 3) Measurement of flow rates and inspiratory mechanics.

#### Results

For a photocopy of Dr. Coelho's results to date, contact IPN.

#### Follow-up

Recheck on a six month basis and re-evaluations as necessary.

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### NEUROMUSCULAR JUNCTION TRANSMISSION DEFECTS IN THE POST-POLIOMYELITIS SYNDROME

By Daria A. Trojan, M.D., Montreal Neurological Institute, Montreal, Canada

Fatigue is a major symptom of the post-poliomyelitis syndrome (PPS), occurring in 88% of 127 patients attending a post-polio clinic at the Montreal Neurological Institute. Muscle fatigability, defined as increased weakness on exertion



improving with rest, is also a feature of PPS, and is reminiscent of the fatigue observed in myasthenia gravis (MG) and amyotrophic lateral sclerosis (ALS). In addition, decrement on repetitive stimulation, and increased jitter on single fiber electromyography (SFEMG), both suggestive of neuromuscular junction transmission defects, have been reported in all three disorders. The anticholinesterase agent pyridostigmine, which can enhance neuromuscular transmission, has been used to treat muscle fatigability in MG and ALS, and also ameliorates generalized fatigue.

We designed an open trial of pyridostigmine in the treatment of fatigue in PPS patients. In addition, we studied the response of neuromuscular junction abnormalities to endrophonium, a short-acting anticholinesterase agent. Sixteen patients were treated with pyridostigmine; ten of these patients underwent stimulation SFEMG testing prior to initiation of pyridostigmine. SFEMG examination with jitter analysis in a muscle fiber before and after injection of endrophonium was performed in these ten patients. Four patients were found to have a positive response (defined as a significant decrease in jitter with endrophonium), and six patients had a negative response (defined as either no change in jitter, or an increase in jitter with endrophonium).

To measure response to pyridostigmine, a mobility index, an activities of daily living (ADL) index, and two fatigue indices were computed for all 16 patients before and at least one month after initiation of treatment. Two patients were unable to tolerate the medication. Ten patients experienced a reduction in their fatigue as seen by an improvement on fatigue indices. Two patients showed improvement on ADL indices, one patient showed improvement on mobility index, and one patient was able to return to work after initiation

of treatment. The four patients with a positive response to endrophonium on SFEMG also showed an improvement in fatigue on pyridostigmine. Four of the six patients with a negative response to endrophonium on SFEMG also had a negative response to pyridostigmine, while the remaining two patients with a negative response to endrophonium were unable to tolerate pyridostigmine.

We conclude that (1) pyridostigmine may be an effective treatment of fatigue in PPS and (2) response of fatigue to pyridostigmine may correlate with improvement of neuromuscular junction abnormalities (as seen by decreased jitter on SFEMG) with endrophonium. Further studies are in progress to determine if a significant correlation can be observed.

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#### SELF CONCEPT AND COPING IN THE POLIO SURVIVOR

By Ruth Wilder Bell, R.N., D.N.Sc.,  
University of Maryland at Baltimore,  
Baltimore, MD

Rehabilitation programs for those experiencing the late effects of polio, while unique to each individual, often have as a goal the reduction of the daily wear and tear on already overused muscles. Life style adaptations designed to conserve energy and stabilize functional level are central interventions for controlling post-polio symptoms. While multiple references to the unique psychological implications of post-polio sequelae and the revival of old coping strategies which interfere with appropriate modification of life style are made in the literature, there is little empirical data regarding the psychosocial implications of the polio experience.

This study examines the relationship between self-coping and coping in polio survivors. In addition to

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### RESEARCH (continued from page 9)

the usual demographic data collected in studies of polio survivors, participants will be asked to describe a recent stressful situation perceived to be related to polio. Self concept will be measured using the Tennessee Self Concept Scale (Fitts, 1965) and coping will be measured using an adaptation of Richard Lazarus's Ways of Coping Scale (Lazarus and Folkman, 1984).

#### Major Research Questions

(1) What are the characteristics of the situations described as stressful to polio survivors?

(2) What are the most frequently used coping strategies? Do the frequencies on the various subscales differ for men and women? Do they differ for those who were disabled with the original illness and are now experiencing a second disability with post-polio sequelae and for those who are experiencing post-polio sequelae as a first disability?

(3) How is self concept related to the extent of the initial impairment? How is self concept related to various coping strategies? Are there gender differences for self concept?

#### References

Fitts, W. H. (1965). Tennessee Self Concept Manual. Nashville: Counselor Recording and Tests.

Lazarus, R. & Folkman, S. (1984). Stress, Appraisal, and Coping. New York: Springer Publishing.

This research is sponsored by Biomedical Research Support Grant No. 1 S07 RR 05973 02, University of Maryland at Baltimore, School of Nursing. Ruth Wilder Bell, R.N., D.N.Sc., and Shirley Damrosch, Ph.D., are the investigators.

## POLIO SURVIVOR POINT OF VIEW OF AGING WITH A DISABILITY

By Jessica Scheer, Ph.D., Post Doctoral Fellow, National Rehabilitation Hospital, Washington, D.C.

I am a cultural anthropologist who started a participant-observer research project in July 1988 at the National Rehabilitation Hospital's Post-Polio program in Washington, D.C. Lauro Halstead opened the clinic in late 1986 when he relocated to NRH from TIRR in Houston, Texas. It's a state-of-the-art outpatient program for persons aging with a disability--providing comprehensive rehabilitation services using a team approach. Clients are initially evaluated in a two-day assessment, and are followed at six week and yearly intervals, or as needed.

My two-year research project, funded in part by the National Institute on Aging, is designed to explore in depth the values, attitudes, and meanings people attach to their experiences with the late effects of polio. I'm interested in documenting the process by which people implement and do not implement the treatment recommendations suggested by clinicians after an initial evaluation at a post-polio clinic. My goal is to record the "native's point of view"--that is, the person's lived experience and to analyze shared patterns and common themes that reflect the cultural construction of the American polio experience in the late 1980s.

I am tracking the treatment intervention process with 75 clients, with initial interviews at the clinic and later follow-up calls. I am also conducting extensive interviews with 15 clients, meeting with them in their homes at several intervals throughout their first year of polio evaluation. My aim is to use the data to communicate effectively to clinicians and rehabilitation service planners the experiences of persons aging with their disabilities.

I'll share an example. One of my informants (anthropologists refer to their research subjects as informants because they inform us) is a very successful lawyer who had polio at age 8 and walked with a limp until age 40 when he started to use a brace. Two years later, due to increasingly severe fatigue, pain and muscle weakness, he now uses a wheelchair for most of the day. During his life, he experienced his disability as a limitation but not a disadvantage. For him, using a wheelchair and learning to manage the late effects of polio were experienced as a "first disability," a shock which evoked a re-experience of his earlier polio. He spoke to me about his experience of using a wheelchair:

"Yes, there's a lot of losses. There are some gains; you can go faster than most people and you can carry more stuff. Thank goodness for the new streamlined chairs--if there is such a thing as a nice-looking wheelchair, then mine is. But I'm still really ambivalent about my feelings towards my disability. I do what I'm supposed to do because I've seen my medical history and I know what's wrong with me and what has to be done. If I kept on walking I eventually wouldn't be able to get up anymore at all. That option to get out of the chair wouldn't even be there. Although there are times when I wonder what I am saving it for? Why don't I keep walking until I can't at all and have a bit more time away from this chair?"

Understanding the values and attitudes people bring to their adaptation strategies is central to providing effective counseling and the timing of treatment interventions. It's important to provide this information to clinicians and health planners as they, too, learn to manage secondary disabilities.

Let me conclude with a pattern I've analyzed from the preliminary data. I've identified two subgroups of

the clinic-based post-polio population: (1) persons for whom the late effects are experienced as a "first disability" and (2) persons for whom the late effects represent a "second disability." The first disability subgroup did not perceive themselves as disadvantaged by their functional limitations, prior to the onset of new health problems associated with the late effects of polio. The second disability subgroup did identify themselves as disadvantaged by their functional limitations prior to the onset of the late effects of polio and now perceive their new health problems as a "double disability."

Rehabilitation professionals need to be sensitized to the world view and values of the first disability subgroup; although initially unwilling to follow treatment recommendations, if respected for their experiences instead of being punished and labeled "resistant," this subgroup shows great promise for a high rate of implementation. For this group especially, learning about the psychological and social costs of "passing into the mainstream" in their own lives is therapeutic in itself.

## **Americans with Disabilities Act (ADA)**

Hearings on the Americans with Disabilities Act have been held in both the House and the Senate. As of late July, 51 Senators and 197 Congressman have agreed to co-sponsor the Act.

To leave a message for both of your senators and one representative, call Western Union 1-800-257-4900 and ask for operator 9565. This service costs \$7.50 and can be charged to a credit card or a phone bill.

## National Polio Awareness Week

On May 4, 1989, Congressman Richard A. Gephardt of Missouri (D) introduced a joint resolution (H.J. Res. 260) which designated May 29 through June 4, 1989 as "National Polio Awareness Week."

IPN thanks everyone who helped make this resolution possible.

Below is a list of the legislators who co-sponsored the resolution.

Mr. Gephardt (for himself, Mr. Gray, Mrs. Bentley, Mr. Lipinski, Mr. Royeal, Mr. Lagomarsino, Mr. McHugh, Mr. Mrazek, Mr. Levin of Michigan, Mr. Roe, Mr. Traficant, Mr. Dymally, Mr. Lehman of Florida, Mr. Matsui, Mr. Stark, Mr. Kostmayer, Mr. Moakley, Mr. Davis, Mr. Wilson, Mr. English, Mr. DeFazio, Mr. Kasich, Mr. Guarini, Mr. Sabo, Mr. Kildee, Mr. Coelho, Mr. Skelton, Mr. Kolter, Mr. Montgomery, Mr. Foley, Mr. Fauntroy, Mr. McNulty, Mr. Tauke, Mr. Bennett, Mr. Horton, Mr. Gunderson, Mr. Hughes, Mrs. Collins, Mr. Fazio, Mr. Schaefer, Mr. Rahall, Mr. Walsh, Mr. Rangel, Mr. Frank, Mr. Volkmer, Mr. Vento, Mr. Nowak, Mr. Florio, Mr. Donnelly, Mr. Owens of New York, Mrs. Boxer, Mr. Miller of California, Mr. Erdreich, Ms. Oakar, Mr. Savage, Mr. Hatcher, Mr. Garcia, Mr. Paxon, Mr. Fish, Mr. Faleomavaega, Mr. Kleczka, Mr. Martinez, Mr. Towns, Mr. Evans, Mr. Dwyer of New Jersey, Mr. Bonior, Mr. Bartlett, Mr. Quilen, Mr. Lancaster, Mr. Crochet, and Mr. Hall of Ohio).

Many individuals and groups requested proclamations from state and local governments. The granted proclamations, as reported to IPN, are listed below.

STATES: California, George Deukmejian, Governor; Nevada, Senator Raggio; New Mexico, Garrey Caruthers, Governor; New York, Mario M. Cuomo, Governor; South Carolina, Carroll A. Campbell, Jr., Governor;

and Tennessee, Ned Mc Wherter, Governor.

COUNTIES: Alpine Co., CA, Donald Jardine, Chair of Supervisors; El Dorado Co., CA, Robert E. Dorr, Chair of Supervisors; San Diego Co., CA, Susan Golding, Chair of Supervisors; and Douglas Co., NV, Michael E. Fischer, Commissioner.

CITIES: South Lake Tahoe, CA, Terry Trupp, Mayor; Saint Louis, MO, Vincent C. Schoemehl, Jr., Mayor; Carson City, NV, Marv Teixeira, Mayor; Reno, NV, Peter J. Sferrazza, Mayor; Sparks, NV, James L. Spoo, Mayor; City of Newport, RI, Robert J. McKenna, Mayor.

## New Post-Polio Clinics

Phoenix, AZ: Cynthia Bachman (N. Chawla, M.D.), Good Samaritan, 1111 E. McDonnell Road, Phoenix, AZ 85062. (602/239/4529).

Portland, OR: Philip King, M.D., Oregon Health Sciences University, 3181 S.W. Sam Jackson Park Road, Portland, OR. (503/279-8505).

## Post-Polio Bibliography

"Ventilator Management in Duchenne Muscular Dystrophy and Postpoliomyelitis Syndrome: Twelve Years' Experience" by Francis J. Curran and Agatha P. Colbert. Archives of Physical Medicine & Rehabilitation, March 1989, Vol. 70. Pages 180-185.

"Neuromuscular symptoms in patients with previous poliomyelitis: a New Zealand study" by Philip C.H. Baker. The New Zealand Medical Journal, March 22, 1989, Vol. 102, No. 864. Pages 132-4.

"Cardiorespiratory Responses to Aerobic Training by Patients With Postpoliomyelitis Sequelae" by David R. Jones, et al. Journal of the American Medical Association, June 9, 1989, Vol. 261, No. 22. Pages 3255-3258.

## Information on...

### Polio Survivor Statistics

In 1987, the National Center for Health Statistics (NCHS) included screening questions in the National Health Interview Survey (NHIS) in order to produce a national estimate of the number of polio survivors in the U.S. Results from this survey indicate that there may be as many as 1.6 million polio survivors, an estimate that far exceeds previously reported estimates. These data are now available on Public Use Data Tapes for research purposes. Summary data will be published in the Advance Data series of the NCHS by the end of 1989.

In the 1987 NHIS, all persons 26 years of age and over were asked to respond to the polio screening questions. These questions identified a national sample of 821 polio survivors. It is possible to conduct a follow-up survey to produce a more precise national estimate of polio survivors and to gather information about the prevalence and nature of the late effects of polio. NCHS is very interested in pursuing such a study and is seeking co-sponsors and collaborators for such an endeavor.

If you are interested in 1) co-sponsoring a follow-up study of the polio survivors identified in the 1987 NHIS; 2) ordering the 1987 NHIS Polio Supplement Data Tape; or 3) getting a copy of an Advance Data on polio survivors (when available), please contact: P. Ellen Parsons, Ph.D., M.P.H., National Center for Health Statistics, Room 2-44, 3700 East-West Highway, Hyattsville, MD 20782.

### Post-Polio Slides

"The Pathophysiology of the Post-Polio Syndrome," a unique series of six slides prepared by a medical illustrator, is available from Frederick Maynard, M.D./Sunny Roller, M.A. of the Post-Polio Research & Training Program, NI2A09

300 N. Ingalls Bldg., Ann Arbor, MI 48109-0491. Advance payment of \$75 is required.

### Conference Proceedings

To purchase Proceedings of National Conference on the Late Effects of Polio (Toronto, November 3-5, 1988), contact Shirley Teolis, Ontario March of Dimes, 60 Overlea Blvd., Toronto, Canada M4H 1B6.

### Conference Proceedings

Proceedings (in German only) are available from the International Conference on the Late Effects of Poliomyelitis and Chronic Underventilation (Munich, April 7-9, 1988). Contact IPN or Uwe Frehse, Westendstr. 93, 8000 Munchen 2, West Germany for an order form. The publication includes a complete index and a listing of individuals and organizations participating in the Conference.

### Survey Results

The Late Effects of Polio: A Descriptive Survey of Post Polio Syndrome in British Columbia is available from Post Polio Awareness and Support Society (P.P.A.S.S.) of British Columbia, 813 Darwin Avenue, Victoria, BC V8X 2X7 Canada, for \$2.50 each (Canadian). The findings "conclude two things: PPS exists, and it is a larger health problem than currently acknowledged by the medical profession."

### Survey Results

Turid Josang, Division Advisor of Norges Handikapforbund, Boks 49, Bryn, 0611 Oslo 6, Norway writes that a comprehensive inquiry form prepared by physicians, physiotherapists, and polio survivors was sent to 1,300 polio survivors in Norway. The report of the research is available in Norwegian from the above address. It is not yet available in English.

### Polio Resources

June Shelley, Library Director, Brandon Township Public Library, 476 Mill Street, P.O. 489, Ortonville, MI 48462, reports a busy

(continued on next page)



## Information on... (continued)

and successful year loaning information about the late effects of polio. The Polio Network serving Michigan contributed \$1,500 to help establish the collection. Contact June for further information.

### Coping Booklet

LaVonne Schoneman, WA Polio Survivors Association, 16734 -8th NE, Seattle, WA 98155, has been writing and editing a coping column in their newsletter for the last two years. A collection of the columns is now available in a 4" by 9" 80-page booklet for \$7. If you are interested in purchasing the booklet or contributing to an upcoming one, contact LaVonne.

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### COPING SUCCESSFULLY WITH POLIO'S LATE EFFECTS

By Jessica Scheer, Ph.D., Post Doctoral Fellow, National Rehabilitation Hospital, Washington, D.C.

COPING SUCCESSFULLY WITH POLIO'S LATE EFFECTS, a videotape prepared by Sunny Roller, M.A., Educational Director, and Frederick Maynard, M.D., Medical Director of the University of Michigan Post-Polio Research and Training Program, was premiered during the Fifth International Polio & Independent Living Conference in St. Louis. The 20-minute video is a lively introduction to the medical issues and psychological concerns facing one-third to one-half of American polio survivors.

Following an introduction by Dr. Maynard on the medical consequences of chronic polio, Ms. Roller, a polio survivor herself, interviews a panel of five middle and retirement age men and women who have learned how to manage their own late effects of polio. She asks them to discuss how they found help, how they budget their energy resources, and how their family and friends

have responded to their changed circumstances. As the panel members share their observations and insights, the audience has an opportunity to hear many concrete tips on how to cope with the late effects of polio.

However, coping is not presented as a series of simple "how to's." Coping is acknowledged to be a process of living with a series of limitations and possibilities.

People who are learning how to manage the late effects of polio will find it particularly useful and satisfying to view the videotape with their family members and friends. The issues raised by panel members in a very matter-of-fact manner could help families and friends start a conversation, perhaps long overdue. Support groups will also find the video to be a welcome program event.

The tape is available on 1/2" video cassette for \$50 and 3/4" for \$75. Payment in advance is required. To order, contact The Post-Polio Research & Training Program, NI1A09-0491 300 N. Ingalls Building, Ann Arbor, MI 48109-0491.

## Post-Polio Directory

Please ADD the following:

### CLINIC

Philip S. King, MD  
Oregon Health Sciences University  
Rehabilitation Clinic  
3181 S.W. Sam Jackson Park Road  
Portland, OR 97201  
503/279-8505

### HEALTH PROFESSIONAL

Sara Marks Tabby, M.D.  
Physical Medicine & Rehabilitation  
1331 E. Wyoming Ave., Suite A-08  
Philadelphia, PA 19124  
215/288-2810



SUPPORT GROUPS

Robert Planthold  
St. Mary's Medical Center  
2200 Hayes Street  
San Francisco, CA 94117  
415/431-6453

Post-Polio Support Group  
Easter Seal Society  
977 Pismo Street  
San Luis Obispo, CA 93401  
805/543-4122

Jim Powell  
Quad Cities Polio Survivors  
1613 12th Street  
Silvis, IL 61282  
309/792-1116

Donna Alexander  
Manhattan Post-Polio SG  
222 Oak Valley Drive  
Manhattan, KS 66502  
913/537-7822

Ernie Switzer  
Blue Mountain Polio Survivors  
20 S. Clinton  
Walla Walla, WA 99362  
509/525-4824

Jerry Taylor  
Blue Mountain Polio Survivors  
613 Ash  
Walla Walla, WA 99362  
509/525-3002

Please make the following CHANGES:

CLINICS

Northwestern University Med School  
Streeterville Center  
Scott Heller  
Michael Minieka, MD  
233 E. Erie Street, Suite 500  
Chicago, IL 60611  
312/908-7950

University of Cincinnati  
Steven Cremer, MD  
Peter Keebler, MD  
University Medical Arts Building  
222 Piedmont Avenue, Suite 3400  
Cincinnati, OH 45219  
513/475-8640

SUPPORT GROUPS

Medford Polio Survivors  
Easter Seal Society  
820 Crater Lake Ave.  
Medford, OR 97504  
503/772-6191

Portland Post-Polio SG  
Easter Seal Society of Oregon  
Carol Newville  
5757 SW Macadam Avenue  
Portland, OR 97201  
503/228-5108

Dom Natale  
Delaware Valley Polio Survivors  
P.O. Box 102  
Flourtown, PA 19031  
215/289-5493

Arnold Snyder  
Delaware Valley Polio Survivors  
P.O. Box 102  
Flourtown, PA 19031  
215/576-5500

Warner Linfield  
Delaware Valley Polio Survivors  
P.O. Box 102  
Flourtown, PA 19031  
215/836-7814

Jeanne M. Carlock, MS. Ed  
Norfolk Area Post-Polio SG  
ENDEPENDEANCE CENTER  
JANAF OFFICE BLDG. 601  
Norfolk, VA 23510

Bonnie Olson  
5944 S. 235th St.  
Kent, WA 98032  
206/854-3867

INTERNATIONAL

Jeannette Shannon  
1092 Flagship Drive  
Mississauga, Ontario  
L4X 2K1  
416/896-0220

Diane Thompson  
13012 - 81 Street  
Edmonton, Alberta  
T5C 1N4

# POTPOURRI

## 1989-90 Flu Vaccine

The Centers for Disease Control (CDC) reports that the World Health Organization has recommended that the trivalent influenza vaccine for use this season contain the following: type A/Shanghai/11/87-like antigen (H3N2); type B/Yamagata/16/88-like antigen; and retain the type A/Taiwan/1/86 (H1N1) component of the current vaccine. This has been ratified by the Food and Drug Administration's Advisory Panel.

## Volkswagen to Pay Conversion Costs

VW/U.S.'s Mobility Access Program will provide \$1,500 toward adapting its 1989 Vanagon Carat or 1989-1/2 Wolfsburg Limited Edition Vanagons to accommodate individuals with a disability. Prospective buyers can call the toll-free hotline, 1-800-444-VWUS, for further information.

## Small Tool Grippers

Hoyle Products, Inc., 302 Orange Grove, P.O. Box 606, Fillmore, CA 93015 (805/524-1211) produces seven different sizes of (vinyl) triangular or round grippers. Contact them for prices and information about their other products.

## Emergency Prescription Service Club

For a brochure describing the services they offer (\$18.50 a year), contact the Emergency Prescription Service Club (EPS Club), P.O. Box 27113, Omaha, NE 68127.

## Sports and Recreation Resource

Sports and Recreation for the Disabled: A Resource Manual by Michael J. Paciorek and Jeffery A. Jones is available from Benchmark Press, Inc., 701 Congressional Boulevard, Suite 340, Carmel, IN 46032. This 393-page book costs \$18.95.

## Catalog for Adaptive Recreation Equipment

For Don Krebs' Access to Recreation, write to Access to Recreation, Inc., 2509 E. Thousand Oaks Blvd., Suite 430, Thousand Oaks, CA 91362.

# Rehabilitation into Independent Living

30th Anniversary Issue Rehabilitation Gazette

In June of 1988, Gini Laurie mailed a letter to many of her Gazette friends. She requested "help in celebrating the Gazette's 30th anniversary. Think back to yourself in 1958. Look at yourself today - knowledgeable in the ways of the world and in the world of disability. Will you think about how you did it? Will you mull over your motivation and rehabilitation?"

The sometimes wonderful and many times painful review and analysis of their lives with a disability resulted in the 30th Anniversary Issue of Rehabilitation Gazette (Vol. 29, Nos. 1 & 2), Rehabilitation into Independent Living.

Lawrence C. Becker, Ph.D., Professor of Ethics at William and Mary, and his wife Charlotte both contributed to this special edition.

The following is excerpted from Dr. Becker's reminiscence.

For the past thirty-six years I have fought hard against being identified as a handicapped boy, son, student, man, philosopher, teacher, husband and so forth--as hard as I have fought against the limitations imposed by my body. And my insistence on excluding the most obvious fact about my life from every public description of me has some of the effects of denial, both on the inside and on the outside. So much so, in fact, that a severely disabled friend once accused me of trying to "pass." That remark still stings--not only because the charge of self-deception is hard to take, but also because it suddenly illuminates for me the absurdity of my walking around, arms dangling, breathing like a frog, acting like 1952 was a very good year.

For the record: 1952 was a very bad year for me, except that I survived it.

There are three things at the heart of my life, and I was advised strongly against all of them: philosophy (it would impoverish and depress me); teaching (there was too much discrimination against the handicapped); and marriage (it would be unfair to anyone foolish enough to agree). I list those in the order in which I ignored the well-meaning advice. It doesn't seem possible to say which has been the most important. If I had done what rehabilitation psychologists and some friends advised, I would now have a J.D. rather than a Ph.D., a partnership rather than a professorship, and a farm in the country rather than a house in the suburbs. Charlotte would (if she remembered me at all) think I was stupid for never having proposed. I would have travelled more widely, but I wouldn't have had the luxury of sabbaticals. I might have written contracts for books, but probably not the books themselves. I would, I suppose, still be 49 years old in that other world, but nowhere near as happy.

There is no secret to this sort of success-without-arms story. Every reader of the Gazette knows that the ingredients are first, second, and last a family that somehow adjusts lovingly to its bad luck and resolutely sets out to keep their horizons wide, and their expectations of each other high. My family simply always assumed that if I lived I would have a full and productive life; that I would go to college; that I would find a way not only to make a living but to have a career that I wanted. What polio had changed was the way in which I would have to work all that out, the extent to which I would be dependent on them, and the degree of difficulty of it all. They coped with this in a way that was largely invisible to me and created an environment in which there

weren't any excuses available to me for doing less than what was clearly possible. My mother, in particular, had an astonishing amount of patience and good cheer. She arranged for me to have a conventional life, adjusted for the lack of arms.

The rest was (and is) work. That and what the psychologists call adjustment. The letter inviting me to write this reminiscence suggested that I try to articulate something about the adjustment part also--something, I assume, beyond the obvious. I'm reluctant to try this, since most of the readers of this journal have already worked these things out for themselves long ago. But the truth is that my ability to cope has been shaped decisively by several discrete events--several discrete utterances, actually--that I have never before tried to write down. I'll try to make them interesting--and short.

Some things are not within your control. On a day in September 1952, after my fever went down, my doctor decided to see whether I could still breathe on my own. He walked into my field of vision in the mirror of the iron lung, made eye contact briefly, said good morning, took out his pocket watch, and without warning went to the foot of the lung and turned it off. It was as if he had pushed my head under water.

Within a day or so, as I now believe, I independently rediscovered most of the truths, and all of the errors, of an ancient and famous book of stoic philosophy called the Enchiridion. It was written by Epictetus, a Greek who had been a Roman slave, and propounds the idea that human beings can control the quality of their lives by controlling their emotional and intellectual responses to events. Some things are within your control and others are not, Epictetus said, but your evaluation of them, and your

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## Rehabilitation into Independent Living

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emotions, are always within your control. (If that sounds familiar, it is. Every recent decade has seen a name brand of psychotherapy based on the idea of rational emotional response.) Practicing this doctrine has some ugly side effects, as Epictetus is honest enough to state baldly, but the overall results are persuasive for someone in an iron lung. It turns out that although it is true that some things are not within your control, you can't really know what the interesting ones are until you try them. That is a fine form of irony.

Never use THE fact. One of the first trips I made in a wheelchair was a forced excursion down the hall from my idling iron lung (I was due back within the hour) to see another juvenile male who had had polio. The nurses didn't know that he and I had been seventh-grade enemies. They rolled me into his room, and he graciously allowed me to wait while he dictated (to a patient Greylady) a letter to his girlfriend. It began with the words "I guess now that I've had polio..."

I wanted to throw up. Until then I had of course been considering the possibility of writing several such letters, like a good little opportunist. But that scene drove the thought, and all of its variations, permanently out of my mind.

Don't patronize people with no feet. This is complicated. It begins with a visit from a woman paraplegic who had just gotten leg braces and learned how to heave herself to her feet. In the flush of her triumph someone told her to wheel down to my room (where I was gasping like a minnow, immobile on the bed) and show off her new talent. She did, against her better judgment, and we were both stricken by the cruelty of the comparisons that are forced on the sick in or-

der to exhort them into greater efforts and better spirits. ("I complained bitterly because I had no shoes, and then I saw a man...") I just cried and turned my head away. She came back later, without the well-wishers, and helped me put this principle into words.

Being easy to love. This was not a discovery. It was a slap in the face. (That is too mild. I was floored by it, and still am.) An ancient married man on a rocking bed, with a level gaze fixed somewhere on the footpedal of my wheelchair, said "I may not be able to keep the wolf from the door but I can make myself easy to love." The hideous brilliance of that principle--its danger and its inescapable logic--is worth a lifetime.

Putting polio at the periphery. This is the last one, mercifully. It took longer to learn, though I heard it repeatedly, in different words, from many friends who had reason to know. It is only half true, but still worth acting on. Stated as a parody of another famous philosopher (Kant), it is this: Act as though your biographer will have no evidence, not even a hint, of the fact that you were crippled.

That puts some things (work, mostly) into perspective. It is also bracing, makes one a more pleasant conversationalist, and (whatever its cost in absurd pretense) yields good results, mostly. I promise.

## IPN Membership Renewal Notices

In July, IPN mailed renewals notices to individuals whose memberships are due this quarter. Please return the card with a check for \$8 so you will receive the Fall Polio Network News (Vol. 5, No. 4).

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# Rehabilitation *into* Independent Living

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**30th ANNIVERSARY ISSUE OF THE REHABILITATION GAZETTE**  
VOL. 29, NOS. 1 AND 2

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This unique collection of life experiences of 40 individuals covers 35 years of rehabilitation into independent living — a total of 1,000 years of experiences. Their guidelines will help others to follow in their footsteps and to live life fully and productively.

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# Calendar

September 15-16, 1989. Colorado Post-Polio Educational Update, Denver Marriott West, 1717 Denver Marriott Blvd., Golden, CO 80401. Contact: Mary Ann Hamilton, 1185 South Williams Street, Denver, CO 80210. 303/722-6945. Alison Kron, Colorado Easter Seal Society, 5755 West Alameda Avenue, Lakewood, CO 80226. 303/233-1666.

October 4, 1989. Conference on the Late Effects of Polio, Holiday Inn, Rts. 512 & 22, Bethlehem, PA. Contact: Beverly Solomon, Ph.D., 2200 Industrial Drive, Bethlehem, PA 18017-2198. 215/866-8092.

October 13-14, 1989. The Third Annual Post-Polio Conference, Boise, ID. Contact: Donna Gummer, Idaho Easter Seal Society, 1350 Vista, Boise, ID 83705. 208/384-1910.

October 20-21, 1989. Post-Polio Support Conference, Napier, New Zealand. Contact: Phillipa Morrison, 2/6 Sanders Avenue, Napier, New Zealand.

November 2-5, 1989. First Pacific Northwest Regional Conference: Managing Post Polio Problems. Airport Inn Resort, Richmond, British Columbia. Contact: Rheta Davidson, 1701 Cedar Hill Cross Road, Suite 402, Victoria, British Columbia V8P 2P9. 604/477-6546.