

# POLIO NETWORK NEWS

International Polio Network

Winter 1991 ■ Vol. 7, No. 1

## U.S. Polio Survivors: The Numbers from Two Sources

*Morbidity and Mortality Weekly Report*, printed and distributed by the Massachusetts Medical Society, annually publishes "Summary of Notifiable Diseases, United States." The following charts were compiled using their 1987, 1988, and 1989 editions. The 1989 edition was published October 5, 1990.

Each edition carries this statement and should be noted:

"Data in this summary should be interpreted with caution. Some diseases such as plague and rabies that cause severe clinical illnesses and are associated with serious consequences probably are reported quite accurately. However, diseases such as salmonellosis and mumps that are clinically mild and infrequently associated with serious consequences are less likely to be reported. Additionally, subclinical cases are seldom detected except in the course of special studies. The degree of completeness of reporting is also influenced by diagnostic facilities available, the control measures in effect, and the interests and priorities of state and local officials responsible for disease control and surveillance. Finally factors such as the introduction of new diagnostic tests (e.g., for hepatitis B) and the discovery of new disease entities (e.g., infant botulism and legionellosis) may cause changes in disease reporting independent of the true incidence of disease. Despite these limitations, the data in this report have proven to be useful in analyzing trends.

"Mortality data are from the National Center for Health Statistics. Each year these data are also published in Vital Statistics of the United States, Vol. II. Data on notifiable diseases before 1960 are obtained from publications of the National Office of Vital Statistics."

**From 1937-1950, the total cases included both paralytic and non-paralytic polio.**

| Year | Reported Cases | Year  | Reported Cases              |
|------|----------------|-------|-----------------------------|
| 1937 | 9,514          | 1944  | 19,029                      |
| 1938 | 1,705          | 1945  | 13,624                      |
| 1939 | 7,343          | 1946  | 25,698                      |
| 1940 | 9,804          | 1947  | 10,827                      |
| 1941 | 9,086          | 1948  | 27,726                      |
| 1942 | 4,167          | 1949  | 42,033                      |
| 1943 | 12,450         | 1950  | 33,300                      |
|      |                | Total | 226,306                     |
|      |                |       | (paralytic & non-paralytic) |

SOURCE: Summary of Notable Diseases, United States edition of the Morbidity and Mortality Weekly Report

(continued on page 4)

## "Prescription for Weakness, Continued"

The following is the contribution of **Jacquelin Perry, M.D.**, Chief, Pathokinesiology/Polio Service, Rancho Los Amigos Medical Center, Downey, CA 90242 USA, to the panel "Prescription for Weakness" at the International Polio & Independent Living Conference in St. Louis. The other panelists were featured in *Polio Network News* (Vol. 6, No. 3).

**DR. PERRY:** Overworked muscles are causing polio survivors problems, so our program is aimed at saving muscles. The evidence at Rancho Los Amigos indicates that the target of the symptoms is the muscle. The symptoms represent accumulated strain from chronic overuse for many years.

David Bodian, M.D., identified that in acute polio in monkeys, 95% of the motor nerve cells were involved (or everything except 5% was involved). Even though the monkeys did not look paralyzed, polio was a very massive invasion. Also, he found that the average recovery of the nerves was 47%, but some monkeys had only 12% recovery and others had 91%. The number 91% always fascinates me because that says there was never 100% recovery. These data simply support that one can have muscle involvement that one was not aware of until a later challenge.

The other contributing factor to problems of today is the method of recovery of function. The Diagram B on page 2 shows three motor nerve cells (I,II,III), each activating a group (four) of muscle fibers. If we lose one nerve cell (Nerve Cell II — — —), the other nerves (Nerve Cells I & II) pick up part of the muscles, as shown by — — —. The result is less of an opportunity for the nerves to trade off between the muscles, resting them. (The diagram shows 3's and 4's when in reality there are 400 motor units and about 400 muscle fibers in each one.)

(continued on page 2)

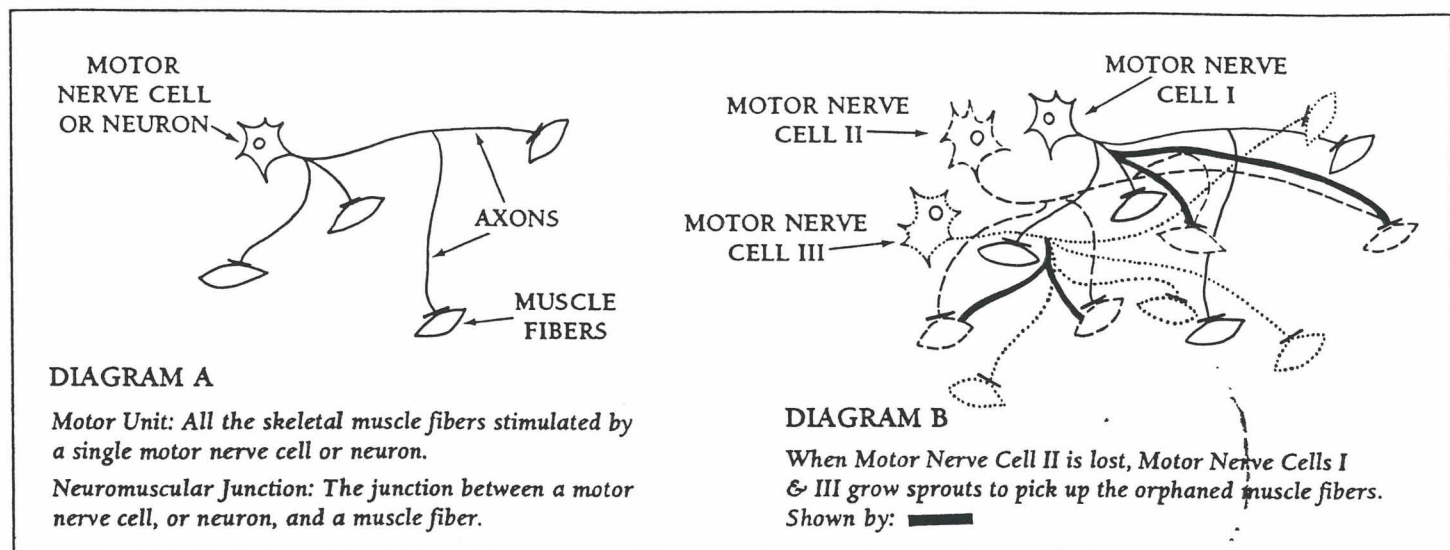
## Inside This Issue ...

|                               |    |
|-------------------------------|----|
| Thoughts on Self-help .....   | 9  |
| Readers & Leaders Write ..... | 14 |



## "Prescription for Weakness"

(continued from page 1)



This re-grouping is a nice substitutive way of recovering muscle use, but the resulting muscles are less efficient because a larger number of fibers is activated with each contraction.

At Rancho Los Amigos, we use dynamic electromyographic recordings of muscle action to determine the duration and intensity of an activity. During normal walking, the quadriceps show a peak effort equaling 30% of maximum ability as the limb is loaded. The effort lasts about 10% of the gait cycle and averages 20% of maximum strength. This means the thigh muscle controlling the knee has a short period of moderate effort and a long period to rest. If the average muscle action is under 20% maximum capability there is full oxygenation and no tissue stress for the brief period of peak effort. This avoids fatigue.

A record of a post-polio patient, complaining of thigh muscle fatigue, shows a very different picture. During walking, the electromyogram (EMG) of a patient with Grade 4 quadriceps showed a peak intensity of 100% as the limb was loaded, and the muscle action continued throughout the rest of the weight bearing period at an average intensity of 60% of maximum. Hence, there was overuse due both to prolonged activity and excessive intensity. In this case, the muscle was substituting for a weak calf muscle group.

Another important point about muscle action is the fact that speed reduces muscle strength. For example, a test of quadriceps strength against a rigid bar registers the most force (100%). When motion at the rate of 60 degrees per second is allowed, the person's maximum strength decreases 25%. Moving at 200 degrees reduces available muscle strength to 50%.

Dynamic electromyographic recordings taken during these efforts show that the muscle was working equally hard during each test. The conclusion is that the faster one moves, the weaker are the muscles. So we recommend that polio survivors slow down.

A muscle is a very elaborate chemical plant that is a self-sufficient system and when you contract the muscle you get force. After the muscle is exhausted, it has to have time to repair itself because a contraction may have torn one of the fibers, and it has to have time to refuel itself so it can contract again. And so, what survivors need to do is give their muscles time for repair and refueling in order to be able to create force again. This is why rest periods are beneficial.

Functionally, a truly normal quadriceps exerts only 20% effort during walking. The quadriceps of a polio survivor may be working twice as hard. A muscle with 40% strength will be exerting two and a half times the normal effort and Grade 3 muscles will be working at 100%. Both situations are signs of overuse.

Survivors with Grade 3 muscles get by with postural substitutions which rely on ligamentous tension. For example, the knee is locked in hyperextension (back knee) so less muscular effort is needed. This introduces its own problems as ligaments also have a limited tolerance for stress. The clinical substitute is a brace, but some polio survivors substitute so cleverly that it is difficult to demonstrate improvement other than pain relief.

Polio individuals need to know their muscle strengths so they can plan safe levels of activity. The easiest way to assess a patient's strength is by a manual muscle



test. It is a convenient clinical procedure, but it must be interpreted carefully or weakness will be missed. A muscle which can accept all resistance given by the examiner is graded as Grade 5 (normal). Instrumented measurement of true normal and post-polio "normal" has shown that a Grade 5 quadriceps averages only 50% of true normal. Similarly, hip extension is only 75%. (These discrepancies were first demonstrated by Beasely, and we have found the same differences.) Grade 4 (good) means the individual can accept moderate but not full resistance, representing only 40% of true normal strength. Grade 3 (fair) indicates the individual can move the limb through its full range but not accept any additional resistance. This is about 20% of normal.

Because of the confusion about Grades 4 & 5, I obtain instrumented test values (i.e. Cybex or other devices) when the patient's general strength is in this range so true strengths are known. Then the patient and I can plan an appropriate activity pattern.

At Rancho Los Amigos we have five programs. These are life-style management, exercise, orthoses, medication, and surgery. The programs differ a bit between the patients with primarily muscular complaints and those with joint problems.

Our major technique is to assist our patients in life-style modification to reduce strain. The program involves myself who sells the program to the patient, if necessary, and the physical therapist and occupational therapist suggesting ways to make life-style modifications.

Orthoses (braces) are very often used to reduce the strain of weak muscles. About 75% of our patients are on life-style modification and 60% of them have braces. (We also try exercise but we will describe that

program later in the conference.) We also do surgery in about 8% of the cases.

With individuals with joint pain, we use orthoses a little more and life-style modification less. The reverse is true with individuals with muscle fatigue and pain. Exercise is of less value and surgery of more value for the patients with joint problems.

We ask every new patient to estimate what they could do at the best time of life and what they can do now. What we have learned from about 200 patients is that both the muscle group and the joint group have already voluntarily reduced their activity by about 50%. We also have learned that the people who had enough muscle weakness to strain their joints have always had less activity.

In planning what to do, both the intensity and the duration of the muscular effort must be considered. The standard is 100% of your strength, not what is normal. If the task is strenuous (hard) and you must exert 75% of *your* strength, use of the muscle(s) should be brief or only 10% of the activity cycle (i.e. the time it takes to walk one stride.) A weak muscle survives by being active only momentarily. In contrast, if the muscle must be active for a long time, such as 50% of the stride, the vigor of the effort can be only 35% of maximum strength without causing strain. These percentages of muscular effort relate to the number of muscle fibers which must be active at that time. It also is an indirect indication of the amount of pressure occurring within the muscle. At 20% effort the muscle pressure is low and oxygen can travel to all of the cells. Higher pressure begins to limit the dispersion of oxygen. This in turn restricts the refueling and repair processes active muscles need.

(continued on page 8)

## 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.

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## U.S. Polio Survivors

(continued from page 1)

**From 1951 to present the reports distinguished between paralytic cases and non-paralytic cases.**

| Year  | Paralytic cases                      | Non-paralytic cases        |
|---|--------------------------------------|----------------------------|
| 1951  | 10,037                               | 18,349                     |
| 1952  | 21,269                               | 36,610                     |
| 1953  | 15,648                               | 19,944                     |
| 1954  | 18,308                               | 20,168                     |
| 1955  | 13,850                               | 15,135                     |
| 1956  | 7,911                                | 7,229                      |
| 1957  | 2,499                                | 2,986                      |
| 1958  | 3,697                                | 2,090                      |
| 1959  | 6,289                                | 2,136                      |
| 1960  | 2,525                                | 665                        |
| 1961  | 988                                  | 324                        |
| 1962  | 792                                  | 148                        |
| 1963  | 396                                  | 53                         |
| 1964  | 106                                  | 16                         |
| 1965  | 61                                   | 11                         |
| 1966  | 106                                  | 7                          |
| 1967  | 40                                   | 1                          |
| 1968  | 53                                   | 0                          |
| 1969  | 18                                   | 2                          |
| 1970  | 31                                   | 2                          |
| 1971  | 17                                   | 4                          |
| 1972  | 29                                   | 2                          |
| 1973  | 7                                    | 1                          |
| 1974  | 7                                    | 0                          |
| 1975  | 8                                    | 0                          |
| 1976  | 12                                   | 2                          |
| 1977  | 17                                   | 1                          |
| 1978  | 9                                    | 6                          |
| 1979  | 26                                   | 8                          |
| 1980  | 8                                    | 1                          |
| 1981  | 6                                    | 0                          |
| 1982  | 8                                    | 0                          |
| 1983  | 15                                   | 0                          |
| 1984  | 8                                    | 0                          |
| 1985  | 7                                    | 0                          |
| 1986  | 8                                    | 0                          |
| 1987  | 6                                    | 0                          |
| 1988  | 9                                    | 0                          |
| 1989  | 5 confirmed cases<br>of 13 suspected | 0                          |
| 1990  | 3 suspected cases                    | 0                          |
| Total   | 104,839<br>(paralytic)               | 125,901<br>(non-paralytic) |
| Total from 1937-1950                                |                                      | 226,306                    |
| Total from 1951-1990                                |                                      | 230,740                    |
| Total from 1937-1990<br>(paralytic & non-paralytic) |                                      | 457,046                    |

## The National Health Interview Survey

Prior to the Fifth (1989) Polio & Independent Living Conference in Saint Louis, **P. Ellen Parsons, Ph.D., M.P.H.**, National Center for Health Statistics (NCHS), 6525 Belcrest Road, Room 850, Hyattsville, MD 20782, contacted International Polio Network and asked us to distribute information sheets about their preliminary numbers on polio survivors from a National Health Interview Survey (NHIS) conducted in 1987. *The purpose of distributing the information was to seek co-sponsors and collaborators to pursue a follow-up study that would further investigate these preliminary numbers.*

The National Health Interview Survey (NHIS) is the principal source of information on the health of the civilian noninstitutionalized population of the United States. It is a continuous survey, initiated in 1957 and conducted by the NCHS since 1960. National data on the incidence of acute illness injuries, the prevalence of chronic conditions and impairments, the extent of disability, the utilization of health services, and other health-related topics are provided by the survey.

A major strength of this survey lies in the ability to display these health characteristics by many demographic and socioeconomic characteristics.

### Purpose and Scope

The NHIS data are obtained through personal interviews with household members. Interviews are conducted each week throughout the year in a probability sample of households. The interviewing is performed by a permanent staff of interviewers employed by the U.S. Bureau of the Census. Data collected over the period of a year form the basis for the development of annual estimates of the health characteristics of the population and for the analysis of trends in those characteristics.

The survey covers the civilian noninstitutionalized population in the United States living at the time of the interview. Persons excluded from the survey are: patients in long-term care facilities, persons on active duty with the Armed Forces (though their dependents are included), and U.S. nationals living in foreign countries.

### Data Collection Procedures

Data are collected through personal household interviews conducted by interviewers employed and trained by the U.S. Bureau of the Census according to procedures specified by NCHS.



All adult members of the household 17 years of age and over who are at home at the time of the interview are invited to participate and to respond for themselves. For children and adults not at home during the interview, information is provided by a responsible adult family member (19 years of age and over) residing in the household. Between 65 and 70 percent of the adults 17 years of age and over are self-respondents. Generally, a random subsample of adult household members is selected to respond for themselves to questions on current health topics that are added each year.

In 1987, all household members 26 years of age and over were asked to respond to the polio screening questions.

## Content of the Questionnaire

The questionnaire consists of two basic parts: (1) a set of basic health and demographic items, and (2) one or more sets of questions on current health topics. The basic items constitute approximately 59 percent of the questionnaire and are repeated each year. These items provide continuous information on basic health variables. Questions on current health topics facilitate a response to changing needs for data and coverage of a wide variety of issues. This combination yields a unique national health data base.

In addition, each of six representative subsamples is asked to respond to questions about one of six lists of selected chronic conditions.

Questions on special health topics change in response to current interest and need for data. In addition to the polio screening questions, the 1987 NHIS included extensive questions on cancer risk factors and a small set of questions on child adoption.

## Below is the list of the questions asked in 1987 about polio.

- 1) Were you EVER told by a doctor or other health care professional that you had poliomyelitis, usually called "polio," whether or not it resulted in physical disability?
- 2) Did you EVER have paralysis of any kind caused by polio?
- 3) Do you NOW have (paralysis of any kind, any deformity, weakness, or) ANY impairment or health problem caused by polio?

(continued on page 6)

## Research into Gastrointestinal Problems of Polio

The Division of Gastroenterology at **Texas Tech University Health Sciences Center** in correlation with the Department of Neurology is conducting an international survey in ***Gastrointestinal Problems of the Polio Survivor***. Many patients who have attended our clinics have complained of various gastrointestinal symptoms, i.e., abdominal bloating, difficulty swallowing, constipation, etc. In order to better understand the relationship of such symptoms to polio survivors and its treatment, we are carrying out an initial survey of patients. We have composed a two-part questionnaire covering gastrointestinal symptoms and neurological symptoms related to the polio survivor. The questionnaire will direct us to the affected organs that will need to be studied.

**Dr. Sinn Anuras**, Director and Chief of the Division of Gastroenterology, will be conducting the work on this project. Dr. Anuras is a world leader in GI complications in Parkinson's patients, spinal cord injuries, Muscular Dystrophy, Familial Visceral Myopathies, Familial Visceral Neuropathies, and chronic pseudo-obstruction. Dr. Anuras is presently writing and editing a book entitled ***Gastrointestinal Motility Disorders: Principle and Practices***.

**Dr. Amitabh Shukla** with the Department of Neurology will be working with Dr. Anuras. We hope that by combining the expertise from the Departments of Internal Medicine and Neurology that we may gain improved understanding of the gastrointestinal aspects of the polio survivor.

If you are a polio survivor and would like to receive a questionnaire and participate in this survey, please call or write to: **Terri Bozeman, RN**, Research Coordinator, Texas Tech University Health Sciences Center, Department of Internal Medicine, Division of Gastroenterology, 3601 4th Street, Lubbock, Texas 79430 USA (806/ 743-3136 or 743-3168 or 743-3130).

### MOVING?

PLEASE SEND BOTH YOUR OLD AND NEW ADDRESSES TO:

INTERNATIONAL POLIO NETWORK,  
4502 MARYLAND AVENUE,  
ST. LOUIS, MO 63108

...WHEN YOU MOVE. POLIO NETWORK NEWS WILL NO LONGER BE FORWARDED BY YOUR POST OFFICE.



## U.S. Polio Survivors

(continued from page 5)

### Some preliminary data.

TABLE 1. Polio survivors 26 years of age and over, by paralytic status: United States, 1987.

| Polio status  | Sample size | Estimated population | % Distribution |
|---------------|-------------|----------------------|----------------|
| All survivors | 821         | 1,634,187            | 100            |
| Paralytic     | 314         | 641,416              | 39.2           |
| Non-paralytic | 473         | 832,852              | 51.0           |
| Don't know    | 84          | 159,919              | 9.8            |

SOURCE: NCHS, National Health Interview Survey, 1987

### Where are we today?

**P. Ellen Parsons** reports that NCHS is very optimistic about receiving funding from various sources to do the follow-up study. We will keep you informed.

**International Polio Network (IPN)**, in its annual letter to leaders, asked that letters be sent to the Centers for Disease Control (CDC), National Institute on Disability and Rehabilitation Research (NIDRR), and National Institute of Neurological Disorders and Stroke (NINDS). *Reports from various sources conclude our letters were very important in bringing the need for more research to the attention of the funding agencies. International Polio Network would like to thank all of the leaders who networked with us to let our concerns be known.*

Because funding sources say that there is not enough interest in polio and the needs are not expressed, IPN also asked, in that same letter, for groups to discuss the following question. *What are our top priorities as polio survivors?* As promised here are the comments received to date.

#### FROM MASSACHUSETTS

(not necessarily in order of importance).

- ☐ More research, especially with respect to rehabilitation.
- ☐ Networking — dissemination of information to individuals.
- ☐ Providing support to and receiving support from other members.
- ☐ Treatment — all types including appropriate exercise.
- ☐ Information as to resources of all types available.
- ☐ Increasing public awareness of PPS and its consequences.
- ☐ Research and information on ventilators for those with pulmonary problems.

#### FROM ILLINOIS

- ☐ Insurance coverage — Post-polio sequelae should be considered a separate illness and not exempt from payment as in a previous illness or condition.
- ☐ Funding sources for braces, equipment and general maintenance of D.M.E. — The membership states that Medicare is not paying for these needs.
- ☐ Transportation — There is not enough or convenient sources of transportation for people with disabilities.
- ☐ Environmental adaptations — Handicapped accessibility into housing and public buildings is very limited or non-existent. Especially noted was lack of handicapped washrooms on the ground floor.
- ☐ Public education — Public needs to be informed and thereby become sensitive to needs of people with disabilities.

#### FROM ILLINOIS

- ☐ Steering polio survivors to see physicians that are now specializing in this problem.
- ☐ Educating polio survivors on the problem.
- ☐ Aiding in getting social security disability status.

*Note:* Psychological support is now a very minor priority. We also believe that research will not find a solution to the problem.

#### FROM WISCONSIN

- ☐ Research — encourage research efforts; define what research needs to be done.
- ☐ Importance of a clearinghouse for post-polio information, ideas, research efforts, etc., such as IPN.
- ☐ Education to health care professionals — need to disseminate correct information on post-polio to internists, specialists, therapists, technicians, etc. We discussed this extensively, especially the need to establish post-polio literature in Med Searches, professional organizations, newsletters, medical



education staff librarians, associations for hospital educators.

- ❑ To serve our members — for support, share information, as resources sharing, social and educational outlet, etc. Educate general public about post-polio issues.

#### FROM KANSAS

- ❑ Polio survivors and local medical personnel need more post-polio syndrome knowledge, especially in regard to the effects and how to deal with them.

#### FROM MICHIGAN

- ❑ Research concerning the fatigue, prevention of new disabilities, appropriate nutrition, the causes and treatment of post-polio syndrome and a holistic approach to treatment (including psychology, homeopathy and nutrition).
- ❑ Establishing a better system to fund health and adaptive equipment needs.
- ❑ Education for the public and for medical personnel.
- ❑ Other priorities: Information, referral and advocacy services to assist with better housing options, including shared living options ; awareness and sensitivity-building programs for improved ergonomically-designed public places (even though many public places are accessible and barrier-free, they still are not as energy-conserving in design as they easily could be) and continued and improved support from other post-polio survivors.
- ❑ Funding for all of the above.

#### FROM CALIFORNIA

- ❑ Our primary concern is the extreme lack of doctors who are knowledgeable of the problems facing polio survivors. It was discussed how important it is to communicate with the anesthesiologist prior to any surgery due to the fact that certain anesthetics should not be used on polio patients.
- ❑ We also discussed the need for more education to make the public aware of the post-polio syndrome — including the medical profession — and of the many needs and problems we are now facing.

#### FROM PENNSYLVANIA

- ❑ To inform the medical community of the need to be more aware of post-polio syndrome which may include information in medical journals. Also, this awareness should be presented in medical schools.
- ❑ To inform the public about the problem, making it possible also to awaken others like us that they are not alone. It is easier to face problems of change when we do not feel alone.
- ❑ Keeping friends and local medical personnel aware as well as the media — especially TV. Some fine presentations have been given.

- ❑ Some attempt has been made to assist the people with disabilities in handling transportation and ease in entering public buildings. Much more is needed.
- ❑ Personally, we survivors need to learn to complain less and appreciate people's attempts on our behalf. Letters of thanks as well as requests would go far to encourage thoughtful attention to our interests.
- ❑ Learning to pace ourselves in work and in leisure activities helps us to conserve energy.
- ❑ Having a good sense of humor "cures" many of our ills!

#### FROM IDAHO

- ❑ Public Awareness and Public Relations
- ❑ Physician Education
- ❑ Family and Self-Education
- ❑ Research

*All groups are welcome to submit the results of their discussion.*

## National Polio Awareness Week

Congressman John P. Doolittle of California will be the primary sponsor of the proclamation for National Polio Awareness Week. Your help is needed.

Please call the local offices of your Congressmen to request their support of the proclamation. (Congressmen will not co-sponsor a proclamation unless they hear from their constituents.) We encourage all polio-related organizations to plan and participate in local activities.

Whereas there are an estimated 650,000 paralytic polio survivors in the United States today;

Whereas knowledge about the late effects of polio is beginning to spread to all polio survivors, the health care community, and the general public;

Whereas the International Polio Network and over 300 local polio support organizations have been instrumental in coordinating efforts to promote research on and increase the awareness of the late effects of polio;

Now, therefore be it resolved that the week of June 1 through June 7, 1991 be designated as "National Polio Awareness Week."



## "Prescription for Weakness"

(continued from page 3)

The calf is the muscle group we use the most during walking and standing and is most likely to be over-used. A functional relationship was found between the measure strength of the calf muscles and the post-polio patients' walking speed. The weaker the muscles, the more slowly the person walked. If you are having symptoms, you will demand less of your muscles if you go more slowly.

What has been our success? We determine success by using the simple scale that patients felt better, worse, or experienced no change. Life-style modification provided some improvement for 95% of the patients with muscle symptoms. Ten percent had no change and 2% continued to get worse. Improvement varied from mild to moderate. In patients with primarily joint complaints, the results were similar. Even in the exercise group, 91% still required life-style modification. So life-style modification is the key.

What about medication? Because pain is a sign of injury, increased tension, swelling or inflammation, or even tearing, I have a hard rule. I will not prescribe pain medication. (I know my patients get them from other people, but I do not prescribe them.) One has to plan a life-style that does not cause pain. I would feel as though I were double-talking, if I said, "Do not get pain," and then prescribe something to cover it up. We do use anti-inflammatory medication, because it does reduce inflammation which is swelling in the tissues. If we can reduce that, we can avoid some of the injury to the muscles. (I know you are thinking, "Well, that it is a pain medication.")

When do we use surgery? The purposes are to correct obstructive deformities or relieve muscle strain. The most common problem is "equinus," a fixed downward foot position. When the deformity is at the ankle, the heel cord is surgically lengthened. If the deformity is in the foot, we will do an osteotomy (a wedge resection and rotation of the foot). We now have an orthopedist in our clinic who specializes in the foot, and we are doing more and more surgery. We protect the surgery with a brace for several months and so far only one patient has needed to continue brace use.

Muscle strain at the ankle and knee is being relieved by tendon transfers which improves weight bearing stability. At the ankle, the muscles which control the foot joints and toes are moved to the back of the heel to supplement the weak and painful calf muscles. At the knee, the hamstring muscles are transferred to remove the strain on weak quadriceps by improving knee extension stability. For both procedures the

results have been good, but we cannot "guarantee" how long these transferred muscles will be adequate. At the time of the surgery, the muscles being transferred had not become painful, and they showed good polio patient record on a gait test.

As a general rule, I say that you can do anything that does not hurt and does not cause fatigue for more than ten minutes. It has been brought up many times that none of us can tell you exactly what you can do because you all have very different habits. You do have to figure it out for yourself, but these are the rules we practice at Rancho Los Amigos.

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# ❖ THOUGHTS ON SELF-HELP ❖

## SELF-HELP PHILOSOPHY\*

*The goal of a self-help group is to empower its members with the tools necessary to make adjustments needed to continue a life of dignity and independence.*

Self-help group(s) ...

- ... share a common health concern.
- ... govern themselves and their agenda with success dependent on each member's feelings of ownership.
- ... may use professionals as resource persons but not as leaders.
- ... provide non-judgemental emotional support.
- ... gather and share accurate and specialized information.
- ... membership is fluid — newcomers are helped by veterans and become veterans who may outgrow the need for a group.
- ... have a cause and actively promote that cause.
- ... increase public awareness and knowledge by sharing their unique and relevant information.
- ... charge small or no fees for involvement and typically struggle to survive.

\* **International Polio Network**, 4502 Maryland Avenue, Saint Louis, MO 63108.

## WORKING DEFINITION OF SELF-HELP\*\*

*Self-help* or mutual support is a voluntary gathering of people who share common experiences, situations or problems and offer each other emotional and practical support based upon the unique perspective only available to those who have shared these experiences.

*Self-help* groups are run by and for group members. Professional providers may participate in the self-help process at the request and sanction of the group.

*Self-help* groups include discussion, sharing information and experiences and other activities that promote mutual support and empowerment.

*Self-help* groups are open to people who have experienced the common concern.

*Self-help* groups require no charge for participation although a nominal donation or dues may be requested to cover expenses.

\*\* Approved by The National Network of Mutual Help Centers at its Annual Meeting October 18-22, 1989.

## THE SELF-HELP ETHOS\*\*\*

Much of the strength of the self-help movement derives from its spirit or ethos, especially its emphasis on empowerment, self-determination, and mutuality.

Helping is not a commodity to be bought and sold.

People who have the problem know a lot about it from the "inside"; competence is based on experience.

There is optimism regarding the ability to change.

The group is key: de-isolation is critical.

The focus is anti-elite, anti-bureaucratic, anti-impersonal.

Small may not necessarily be beautiful, but it is the place to begin: the small group, the personal, the informal, the simple, the direct.

Do what you can. One day at a time. You can't solve everything at once.

The consumer is a producer of help and services.

Helping is at the center: knowing how to receive help, give help, and help yourself.

The orientation is noncompetitive and cooperative.

People who have the problem are part of the solution.

\*\*\* "The Self-Help Reporter," National Self-Help Clearinghouse, 33 West 42nd St, New York, NY 10036.

## SELF-HELP RESOURCES

*International Newsletter*, E. Van Evenstraat 2C 3000 Leuven, Belgium. A tri-monthly newsletter from the International Centre on Self-Help and Health. Editor-in-chief: Jan Branckaerts.

*Post-Polio Support Group Philosophy, Guidelines, and Resources* is prepared by International Polio Network (IPN). Send \$5.00 to IPN, 4502 Maryland Avenue, St. Louis, MO 63108 (314/361-0475).

*The Self-Help Sourcebook* is a comprehensive national guide to finding and forming mutual aid self-help groups. Includes updated contacts, index and descriptions for over 600 national and model self-help groups, provides general how-to's for starting groups; lists world-wide self-help clearinghouses and over 100 national toll-free telephone numbers. Has resource sections on rare and genetic illness and home computer networks. Send \$9.00 to Self-Help Clearinghouse, Attn: Sourcebook, St. Clares-Riverside Medical

(continued on page 10)



## Thoughts on Self-help

(continued from page 9)

Center, Pocono Road, Denville, New Jersey 07834 (201/625-7101 or TDD 201/625-9053).

The National Self-Help Support Centre in London keeps a register of self-help activity in Britain. Coordinates local, national, and Black and ethnic minority self-help workers networks, organizes training programs, publishes a directory of local self-help clearing-houses and produces a quarterly newsletter called MASH (Mutual Aid and Self-Help). Contact: Mai Wann, National Self-Help Support Centre, NVO, 26 Bedford Square, London WC1B 3HU England.

National Council on Self-Help and Public Health, Suite 182, 310 Maple Avenue, West, Vienna, VA 22180. Formed in response to recommendations from the Surgeon General's Workshop in Self-Help and Public Health (September 1987).

National Self Help Network News, CEF Crisis Helpline, Inc., 36 Brinkerhoff Street, Plattsburgh, NY 12901.

SHALL (Self-Help Alliance), Mrs. Lee Miller, 68-37 Yellowstone Blvd., Apt. C-41, Forest Hills, NY 11375. Established as a coalition of self-help groups and self-helpers nationwide.

Working with Self-Help, edited by Thomas J. Powell, published by National Association of Social Workers, Inc. Covers "Understanding and Enhancing the Basic Mechanisms of Self-Help," "Different Types of Organizations," and "Considerations and Approaches Relevant to Working with Self-Help Groups," with attention to minorities.

The Self-Help Way: Mutual Help and Health by Jean Marie Romeder provides an overview of the growth and development of the self-help groups, while probing into the dynamics of the "self-help way." Available from the Canadian Council on Social Development, P.O. Box 3505, Station C, Ottawa, Ontario K1Y 4G1, Canada for \$16.50 postpaid.

Handling Difficult Behavior at Meetings cites 19 very specific problem behaviors and lists a variety of suggested actions that group leaders can take to manage each situation constructively. Available from Marshall House, P.O. Box 5365, Santa Monica, CA 90405 for \$4.45.

Helping One Another: Self-Help Groups in a Changing World by Alfred H. Katz and Eugene I. Bender is a 264-page book in which the authors analyze how and why groups change lives, relate developments to the changing social/political/economic scene and discuss the future. Available from The Third Party Publish-

ing Company, P.O. Box 13306, Montclair Station, Oakland, CA 94661-0306 USA for \$23.95 (\$25.95 in CA and \$28.95 for other countries).

The Self-Help Group Leader's Handbook: Leading Effective Meetings is a compilation of information gleaned from working with groups for over three years (post-polio included). Send \$12.50 + \$3.50 (s&h) to RTC/IL, BCR/4089 Dole, University of Kansas, Lawrence, KS 66045 USA.

Surprise Findings of A Support Group Leader, or What in The World Does One Do Now? by Charlene Bozarth is available from Polio Network of Michigan, 15235 Ackerson Drive, Battle Creek, MI 49017 USA for \$5.

## Suggestions for Leaders

The following advice for support group leaders was excerpted from a column called *Clearinghouse Advisor* by Kari Tomashik and Toni Young featured in *Helping Ourselves*, a newsletter from the Michigan Self-Help Clearinghouse, 109 W. Michigan, Suite 900, Lansing, MI 48933.

### Choosing a Self-Help Group

Often people seek out self-help groups in an effort to be understood by others in similar circumstances. People look for a chance to share feeling and gain reassurance that they are not alone in their struggles. Self-help groups offer the opportunity to gain knowledge about the problem and as well as how others deal with their concerns. In pooling their collective knowledge, self-helpers have discovered new ways of dealing with old problems, which can lead to a renewed sense of hope. Some people search for groups that advocate for rights or attempt to change unfair laws and practices.

It may be necessary to attend more than one meeting in order to assess whether a particular group is for you. Self-help groups are different from other forms of helping. For one thing, successful self-help groups encourage a balance between giving and receiving among members. Long-time members often serve as a source of inspiration to new members who are just beginning to deal with their problems. It's not unusual for new members to "receive" more in the beginning and since "those who help are helped most," veteran members also benefit from their role in the group.

Self-help groups have different ways of accomplishing their goals, and may be formal or informal. Generally, they provide a friendly atmosphere where people can be treated as equals, where no one "authority" presides. One group "Going on After Loss" based in Hamtramck, states, "When people are provided with information and an environment that offers comfort



and reassurance for however long they may be in need of it, the potential for healing and growth increases."

### **Foundations of a Self-Help Group**

There are currently no ethical standards or monitoring principles which guide self-helpers within their groups. In fact, it may not even be a desirable idea to establish them for many reasons. The self-help movement has thrived in recent years, and this is true at least partially, to the absence of complication, bureaucratic regulations, paperwork, waiting lists and other common elements of our daily lives. It is simply people helping other people with a problem they share, and receiving support at the same time.

Another situation may be decisions about collecting fees or dues. The group should be absolutely certain there is a need for fees or dues, before setting any rule. Self-help groups have generally avoided charges of any kind, opting for a voluntary donation type of approach. Even if the group needs to pay for meeting space, for instance, the group should consider how to ensure everyone's participation. Perhaps people can still make voluntary donations, regardless of income or the group can try to find free meeting space.

Confidentiality is also important for self-help group members to examine. People need to feel that "what's said here stays here" so they are free to talk about their concerns. Their identity should not be revealed to people outside the group. This relates to philosophies of mutual support and respect.

Situations in which group members are carefully screened, given forms to sign, given lists of arbitrary rules whether written or verbal are contrary to self-help philosophies and definitions. Likewise, the collection of mandatory fees or charges runs counter to the foundation of the self-help movement. Attendance at groups should be a voluntary act, rather than by court order or by intimidation of a group leader.

It's important for self-help leaders to understand that they are providing a valuable service to the community, a service that is different from that of professional human services. Don't let others pressure your group to become more professionalized than you want it to be!

### **On Leadership**

Promoting leadership in others is an important responsibility in a self-help group. Initially, people find tremendous support from knowing they are not alone and their feelings are respected and understood. However, the structure of the group can encourage or discourage members' participation. As a leader, you can help promote a safe environment where people can express emotions, share disappointments and

accomplishments. You can establish a tradition of participation by all members. Appreciating people for their assistance is also effective in encouraging them to experience, using "I" statements, encourage others to speak from their own experience as well. When you share your knowledge and feelings other people may learn how to share also.

Active listening is important to creating a safe environment in self-help groups. Some methods of active listening are: clarifying what a person has said before responding; giving specific feedback; empathizing with the person's feelings; and reflecting back what the person is saying. Some twelve step groups have a rule called no "cross-talk" which means you cannot respond, comment or give opinions when another person is speaking. When it is your turn you may comment, but should do so only as it relates to yourself. This is effective in preventing people from giving unwelcome advice.

When each person takes personal responsibility for his/her own concerns, within a supportive environment of friends, then together the group can work out mutual problems. The whole idea behind the self-help movement is to provide a place where people feel free to express themselves in a non-judgemental atmosphere. Dependency is not encouraged, rather the leaders and members assist each other, helping others and being helped.

Leaders do not have all the answers. They cannot patch up or solve someone else's problems. Instead guidance and encouragement are provided. With encouragement, people discover their own strengths and learn that they do have the ability to solve their own problems.

### **Contact Persons**

Another concern raised by self-help leaders is that people come to meetings with incorrect impressions of what the group will offer. The contact person plays an important role in educating potential members about what the group does and does not do for members. For example, the contact may explain to callers that the group offers emotional support, but cannot supply any quick or easy solutions to their problems.

Sharing leadership responsibilities between several group members has also been suggested. For instance, the person(s) assigned as group contact(s) may not be expected to fulfill other roles such as planning meetings, engaging speakers, or recruiting new members. In addition, the group may decide how their activities should be presented to interested persons and put it in writing for future contacts. Groups may even want to

*(continued on page 12)*



## Thoughts on Self-help

(continued from page 11)

establish loose guidelines which describe how to handle particular situations that tend to come up repeatedly.

### RESOURCES

**The 1991 Post-Polio Directory** will be available soon to survivors (\$2.00), health professionals (\$15), and institutions (\$25). Contact: G.I.N.I., 4502 Maryland Avenue, Saint Louis, MO 63108 USA (314/361-0475). Please specify 1991.

The Brandon Township (Michigan) Library has a special **Post-Polio Collection** available throughout the country. Contact Gwen Prunte, Brandon Township Library, 476 Mill Street, P.O. Box 489, Ortonville, MI 48462 USA (313/627-6449) for a listing of the collection.

**One Shoe Crew**, 86 Clavela Avenue, Sacramento, CA 95828 USA (916/364-7463). For a \$2.50 fee, the service registers individuals who want to find a shoe partner. There is a \$10.00 fee when a partner is found. Write or call early in the morning Pacific Standard Time.

**National Odd Shoe Exchange**, P.O. Box 56845, Phoenix, AZ 85079 USA (602/841-6691). Non-profit charitable agency that assists amputees and people with different size feet.

Many survivors received services from **vocational rehabilitation** during the '60s and many were denied. If the late effects of polio are causing problems with employment, contact your state's vocational rehabilitation office to request assistance "to gain, retain, or regain productive employment."

Many survivors have expressed an interest in "donating their body" to science. Contact International Polio Network for detailed information on a **tissue donor program**.

Personal service available from the **Social Security Administration** from 7 a.m. to 7 p.m. each business (800/2345-SSA.)

The late effects of polio are mentioned in the Program Operations Manual Systems (POMS), Part 04, Section DI 24580.010. To receive this and a 6-page question and answer sheet about **Social Security Disability**, send \$2.00 to International Polio Network, 4502 Maryland Avenue, Saint Louis, Missouri 63108 USA.

The **Directory of Independent Living Programs** will be available soon for \$8.50 from ILRU, 3400 Bissonnet, Suite 101, Houston, TX 77005 USA (713/666-6244). Please specify 1991. Independent Living Centers (ILCs) are an excellent resource for all disability issues, especially state issues such as funding for personal care assistance, insurance risk-pools, etc.

The **National Disability Action Center**, 2021 L Street, N.W., Suite 800, Washington, D.C. 20036 USA (202/467-5730 voice/TDD). Timothy M. Cook is director of this organization dedicated to protecting the civil rights of people with disabilities.

**NARIC (National Rehabilitation Information Center)** provides information on a wide-range of disability related topics. Call (800/346-2742). NARIC also sells mailing labels of extensive mailing lists.

**ABLEDATA** is a database which contains more than 16,000 commercially-available products from 2,000 manufacturers. Contact The Adaptive Equipment Center at Newington Children's Hospital, Newington, CT or call (800/344-5405). ABLEDATA is also accessible by computer users. Contact BRS Information Technologies by calling 800/345-4BRS.

For a free booklet, **How to Choose a Home Care Agency**, contact: The National Association for Home Care, 519 C Street, N.E., Washington, D.C. 20002 USA.

**Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors** is available from International Polio Network, 4502 Maryland Avenue, St. Louis, MO 63108 for \$6.75 postpaid. Bulk rates are available.

**Rehabilitation Gazette** is the biannual newsletter of Gazette International Networking Institute which is described as a journal "written by people with disabilities for people with disabilities." Its focus is cross-disability, and we welcome your articles or letters sharing your experiences, particularly solutions or "what works for me."

**I.V.U.N. News** is also a biannual newsletter of Gazette International Networking Institute. It informs and networks ventilator-users and health professionals interested in home mechanical ventilation. Your articles are welcome.

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## Handicapping Language\*

*"Language can reinforce stereotypes and misconceptions. Using the wrong word can label, stigmatize, anger and detract from the message. The media can reinforce negative stereotypes, or it can help change attitudes towards people with disabilities by portraying them and their conditions accurately ...*

*"... general rules for writing about people with disabilities."*

**PEOPLE WITH DISABILITIES:** "Handicapped" is still used by the media to refer to people with disabilities. But the word has a negative connotation for many people, so more social service agencies and disability publications are replacing it with "person with a disability." Nowadays, handicap describes a condition or barrier caused by society or the environment, i.e., "She is handicapped by inaccessible transportation," or "stairs are a handicap to him."

**PERSON FIRST:** The person precedes the disability, both figuratively and literally. It's "persons with disabilities," and "person with cerebral palsy," not "cerebral palsy victim."

**ADJECTIVES AREN'T NOUNS:** Use an adjective as a description, not a category or group, i.e., "people who are disabled," not "the disabled," and "people with visual impairments," not "the visually impaired."



**AVOID PITY:** People with disabilities aren't "victims." As one woman who uses a wheelchair noted, "I'm not a wheelchair victim. Wheelchair victims are the people I bump into with my footrest at the supermarket." Nor should people be described as "inspirational" or "courageous" just because they have a disability.

**AVOID BEING CUTE:** Terms like "physically challenged," "special" and "differently-abled" are patronizing. If appropriate, note that a person has a physical, sensory or mental disability and leave it at that. Also, people without disabilities aren't "normal," because that infers that people with disabilities are abnormal. Rather, they are "non-disabled."

**GERMANENESS:** People with disabilities should be treated just like everyone else. You wouldn't mention the physical condition of a non-disabled person unless it was germane to your story, so unless a person's disability is relevant, don't mention it.

\*Excerpted from a brochure published by **Illinois Department of Rehabilitation Services**.

## Writing Guidelines Available

RTC/IL, 4089 Dole, University of Kansas, Lawrence, KS 66045 USA has a pamphlet, *Guidelines for Reporting and Writing about People with Disabilities*, available for 25¢ each and 18¢ each for orders over 100 (postage and handling not included.) Call 913/864-4095 for larger orders.

## National Cristina Foundation

The phrase, "people with differing abilities," was awarded a privately donated prize of \$50,000 in a contest designed to find a word or phrase which focuses on the **abilities** of people with disabilities. The new phrase is not intended to replace other terminology — rather it should be considered a fresh concept to help society focus on each individual's unique qualities.

Nearly 70,000 people entered the National Cristina Foundation's (NCF) "Create A New Word Contest" which sought to call attention to some of the barriers people with disabilities face, particularly when seeking employment.

The National Cristina Foundation (NCF) is the only not-for profit organization directing commercially obsolete and surplus computers, software, peripherals, audio and video equipment to educational and training facilities for people with disabilities, the disadvan-

taged, and students at risk of failing, throughout the United States.

➤ For more information or to donate equipment, call 1-800-CRISTINA.

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## Polio and Ageing Studied in England

Gerry Zarb, Senior Research Assistant, **Thames Polytechnic London**, notified polio survivors in England through an article in *The Bulletin* of the **British Polio Fellowship** that he was conducting a survey on the "experiences and needs of people with a long-term disability or disabling illness who are now also experiencing the ageing process." He reports that he has been contacted by a large number of polio survivors volunteering to take part in the survey. His group will not be able to interview everyone who replied. They do hope to complete interviews with up to 150 people, at least a quarter of whom would be polio survivors. A short preliminary report should be ready in Spring, 1991, and the final report in early 1992.

However, early indications are that the vast majority of polio survivors who contacted them have indicated that they are experiencing late effects of polio; many have explicitly identified these changes as being related to post-polio syndrome. Most people said that the medical profession is showing little interest in post-polio syndrome and do not seem to be doing much to investigate its causes or the possibilities for alleviating some of the problems which people are facing. The perception in England is that the medical profession in the United States is taking a more positive approach to post-polio syndrome.

Thames Polytechnic recently completed the first UK study on ageing with spinal cord injury. One of the important findings from the study was that many people with long-term spinal injuries (20 years plus) are experiencing physical changes which are very similar to post-polio syndrome. These changes typically occur in the period 20-30 years post injury, and many did describe the changes as being like the onset of a second disability. Copies may be obtained from the **Spinal Injuries Association**, Newport House, 76 St. James's Lane, London N10 3DF, England, who commissioned the study.

**Dr. Zarb** is interested in receiving any papers or references relating specifically to the implication of

(continued on page 16)



## Readers & Leaders Write...

### ABOUT BRACING FROM NEW YORK

"I want to tell you about the miracle of wearing a brace again after not wearing one from July 1948 to October 1990 — 42 years.

"When I was first told several years ago that I should go back into a leg brace my brain said, 'If it has to be — it has to be!' The rest of me said, 'Oh, NO! We're going backwards. We're going to fight it.' Well, I was 'good.' I had a brace made.

"However, this particular orthotist was one that believed that the longer you wear a brace, the more comfortable you will feel in it. He also thought that it would be 'OK' once I was able to get it on. You see, in addition to my right leg having no power from the hip down, I had polio in my right hand which left me with what is called 'flat palm.' To explain it simply, I cannot stretch with my fingers and I cannot grab items the way someone else can. That made it impossible for me to put on the brace. Needless to say, that brace did not work out.

"Two years later I went to another orthotist in Suffolk County. To his credit, this young man tried very hard. He made me three different braces. The first was a short brace that started mid-calf and went up mid-thigh. It was easy to get on but, due to my gait, it slid down as soon as I started walking. The next one was a slightly longer version extending higher to my hip. Unfortunately, it also slid around. The last one we tried was a full-leg brace with a foot plate in the shoe. When the orthotist put it on and then put my shoe on, it was fine. HOWEVER, it was impossible for me to do it. So there went the fourth brace into the closet.

"Just about that time our support group was arranging with St. Charles Hospital in Port Jefferson, Long Island, NY, for seminars with different medical personnel each week. The week that we had the orthotists was very enlightening. The young men work with children who have birth defects, cerebral palsy, etc. They also make braces for kids that have no hands.

"They told that if I lost some weight, they would guarantee a brace that fit and that I would be able to get it on by myself. Well, I lost the weight and one of the young men (**Martin Mandelbaum**, 5225-21 Neconset Highway, Port Jefferson Station, NY 11776 USA) was true to his word. Marty cast me for a long leg brace. To get what he wanted, he sent the cast to Canada.

"The brace is unique in that it has two kinds of plastic. The bottom part, including the foot pad, is a firm plastic. This goes to mid-calf. The upper part, which goes around the thigh, is of a flexible plastic lined with soft leather. Instead of the metal bars up the sides with hinges on both sides and a locking device in the back, this one

(as my knee locks itself) has a figure-eight-type thing on the outside of the leg. The brace is held on by a strap approximately 4" down from the knee, a 6" wide piece of elastic going around the thigh and "velcroing," and a third strap going from the 4" down from the knee on the outside around the back of the knee to meet 2" above the knee. And, it works!

"It was then discovered that, although my left leg has always been my strong one, the ankle joint was riddled with degenerative arthritis. My orthopedist, Dr. Joseph Farrell, said that a short ankle brace would be helpful in avoiding surgery and fusing the ankle. Marty came through again with a short (mid-calf), firm, plastic brace with two velcro straps going around.

"As much as I fought it previously, all I can say now is that this makes it easier for me to get around, and, hopefully, to allow me to continue getting around for a few more years.

"If anyone would like to talk to me about these braces, please contact me." **Barbara Goldstein**, 9 Hedgerow Court, Commack, NY 11725 USA (516/499-5477).

### ABOUT BRACING FROM ILLINOIS

"Since I have received information from my *Polio Network News*, I would like to share information with other readers.

"I have been going to Keller Orthotics Inc. for quite some time now, and they have always been concerned with the fit and any needs I may have. They are a certified orthotic service.

"They have 2 locations in the Chicago area. Keller Orthotics, 2451 N. Lincoln Ave., Chicago, IL 60614 USA (Peter Keller — 312/929-470 0) and Keller Orthotics, 6AE Northwest Hwy., Mt. Prospect, IL 60056 USA (Warren Nelson — 708/394-1182)." **Mary Albert**, 203 B Emerson Ct., Bloomingdale, IL 60108 USA.

### FROM GERMANY ON VISIT TO CHICAGO RESEARCH CLINIC

"In 1954, at the age of eight, I had polio and was left with a slight paralysis of the right upper leg including muscle weakness and joint problems in the knee. For 33 years I managed with these problems quite well. Then I noticed an increasing muscle weakness in both arms and legs. Visits to my doctors did not clarify the reasons for this weakness. A new "polio" was excluded, of course, as polio is considered "out" in Germany. By accident my family doctor read an article on post-polio syndrome in a medical journal. This article also mentioned that there have been some research studies on former polio patients.

"During vacation in New Jersey in summer 1989, I contacted a local self-help group and a surgeon. After a thorough checkup this doctor concluded that my prob-



lems might be post-polio syndrome. Thanks to this local support group I heard about **Polio Network News**. I subscribed because I wanted to get into the matter myself.

"In **Polio Network News**, I read a report of a research program conducted by **Dr. Raymond Roos**, from the University of Chicago. Dr. Roos and his team examine the sprouts of motor nerve cells for anatomical abnormalities using a biopsy of the anconeus muscle. With electron microscopy, they are able to look at the actual terminal nerve sprouts, as well as the muscle itself and the neuromuscular junctions. [The neuromuscular junction is abnormal in the case of another neuromuscular disease (myasthenia gravis) that shows fatigue as a prime clinical symptom as does post-polio syndrome.]

"As this team was interested in recruiting patients for these tests, I contacted Dr. Roos. In March 1990, a biopsy study on the anconeus muscle of my right arm and EMG studies were done. The findings of these studies showed anatomical changes with ongoing denervations and electrical abnormalities correlating with increased muscle fatigue when stressed. After these studies, I was told for the first time that I had had polio in all four extremities.

"My main problems at the moment are muscle weakness, muscle pain, muscle atrophy, and swelling in both arms and legs. I was advised to reorganize my daily life, e.g., to relax more often and not to work too much. Every day I do some physical exercise and once a week I go swimming. I also do some transcutaneous nerve stimulation. Dr. Roos also recommended that I use medication containing pyridostigmine. As a result of following all of these suggestions, I do not feel so tired anymore and feel quite well. [The Summer 1989, **Polio Network News** reported from a successful trial using pyridostigmine by **Dr. Daria A. Trojan**, Montreal, Canada.]

"The findings of these tests in Chicago have been very useful for me, my doctors in Germany, and for Dr. Roos and his team. All these checkups have been free of charge, and I was happy to get this done by experienced specialists such as Dr. Roos and **Dr. Maselli**. However, the present findings must be confirmed by additional biopsies and EMG studies. Therefore, it would be helpful if more survivors would participate. Interested readers should contact Dr. Raymond Roos, Dept. of Neurology, University of Chicago, Medical Center, 5841 South Maryland Avenue, Chicago, IL 60637 USA." **Renate Schindler**, Ortlehnerstr. 54, D-8269 Burgkirchen, GERMANY.

## FROM AUSTRALIA

The Post-Polio Support Group of Southern Australia will officially launch the new book **The Late Effects of Polio — Information for Health Providers** by Charlotte Leboeuf on February 24, 1991.

The book was funded by the Commonwealth Department of Community Services. Also introduced was the **Hand-**

**book, A Practical Approach to The Late Effects of Polio** and the video Post-Polio Syndrome. Both of these were funded by Julia Farr Foundation. Contact: **Beth Brodribb**, P.O. Box 493, Hawthorn 3122, Australia, Telephone: 819-4055, FAX 818-2967

## FROM CZECHOSLOVAKIA

"The First Medical Conference on Post-Polio Syndrome in Czechoslovakia took place at the Recreation Centre of Czechoslovak Union of Disabled Persons at Hodonin near Kunstat on 13-15th November 1990.

"Fifty-one doctors beside a number of selected physiotherapists took part with two German doctors, who participated thanks to your announcement of the Conference in the **Polio Network News**. Several papers were read. I acquainted the participants with Gini's life and G.I.N.I.'s publications. All papers will be published in Czech Proceedings next year, and I will send an English summary of medical opinions." **Dr. Ala Wokoun**, Chabarovicka 1333, 182 00 Prague 8, Czechoslovakia, Europe.

## FROM MASSACHUSETTS ON SOCIAL SECURITY

"I am writing to you out of the growing concern in regards to the Social Security Administration's budget and staffing cutbacks which have been imposed on Disability Determination Services (D.D.S.) across the nation.

"Over the past four years there has been evidence of a serious breakdown in services to persons with disabilities due to these cutbacks. The Massachusetts D.D.S. Advisory Committee has witnessed backlogs and diminishing allowance rates in our state, and we hear of similar backlog in other states.

"The backlog of pending cases rose by over 94,000 during F.Y. '90 due to a higher than expected number of receipts per the level funding. The nation was left with 484,941 initial reconsideration and OHA cases pending at the end of F.Y. '90. This was a 24% increase over those pending at the end of F.Y. '89.

"Eighty percent of the states report that their pending cases are so high that it deters them from completing cases in a timely manner. It is expected that these backlogs will occur again this fiscal year.

"This problem has been addressed before at Congressional Hearings where D.D.S. representatives testified on behalf of their own agency. And, we have been holding meetings with the Massachusetts Congressional Delegation members expressing our concerns.

"To date things are beginning to improve. We now have the support of **Social Security Administration Commissioner Gwendolyn King** and **Secretary of Health and Human Services Dr. Louis Sullivan**.

(continued on page 16)



G.I.N.I.

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St. Louis, MO 63108-2915  
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## **Readers & Leaders Write ...**

(continued from page 15)

"Commissioner King responded to requests for more staff and money by asking for a contingency fund tap plus a supplemental appropriation and by pushing for an adequate F.Y. '92 budget. She has submitted her requests to Dr. Sullivan, who in turn asked for the funds from the Office of Management and Budget (OMB). Acting for the OMB, Richard Darman turned down Dr. Sullivan's request. However, it has been reported that Commissioner King and Secretary Sullivan are not accepting Darman's denial and plan to meet with President Bush to urge him to approve the funding.

"To secure the necessary funds, the voices of people with disabilities, their families, and friends need to be heard.

"Write or call your Congressman and Senators. Ask them to support an increase in the Social Security budget earmarked for D.D.S. in F.Y. '92." **Kathleen Simpson**, Massachusetts D.D.S. Advisory Commission, Chairperson.

## **Polio Network News**

### ◆ SUBSCRIPTIONS ◆

By the time you receive this newsletter, we will have secured and installed a new computer program. Some names were electronically transferred and some were re-entered. Errors probably occurred. PLEASE SEND US THE NAME, ADDRESS, AND MONTH OF RENEWAL OF ANY INDIVIDUAL WHO SHOULD HAVE RECEIVED THIS NEWSLETTER OR ANY EARLIER ISSUES. Your assistance and patience are greatly appreciated.

Some of you should have received renewal notices by now. However, we opted to wait until we were caught up on our publications. You will be hearing from us in the near future. If you have any questions, please write or call.

## **CALENDAR**

**"Polio-Towards 2000,"** Australian Polio Network, April 12, 1991. Contact: Beth Brodribb, P.O. Box 493, Hawthorn 3122, Australia (819 4055).

**Madison Area Post-Polio Support Group Annual Meeting,** Howard Johnson Hotel & Conference Center, April 20, 1991. Contact: Ms. Cleo Eliason, Easter Seal Society of Wisconsin, 101 Nob Hill Road, Suite 301, Madison, WI 53713 USA (608/277-8288).

**Ohio Polio Network Post-Polio Conference,** Holiday Inn on the Lane, Columbus, OH USA, August 24, 1991. Contact: Betty Sugarman, Ohio Easter Seal Society, 2204 S. Hamilton Road, Columbus, OH 43232-0462 USA (614/868-9126).

**Mississippi Polio Survivors Association Quarterly Meeting,** Busey Auditorium, Baptist Medical Center, Jackson, MS, September 14, 1991. Contact: Richard Swanson at 601/563-8237 or Robert Thayer at 601/924-9284.

**Second Colorado Post-Polio Educational Conference,** Westin, Denver, CO USA, September 13-14, 1991. Contact: Alison Kron (303/233-1666).

**The Second Texas-Oklahoma Post-Polio Symposium,** Wichita Falls Ramada Inn, September 21-22, 1991. Contact: Barbara Miller, 4503 Allison, Wichita Falls, TX 76308 USA (817/691-3497).



## **Polio and Ageing**

(continued from page 13)

ageing with polio for provision of health care and independent living/support services. He has several papers on post-polio syndrome but has not been able to obtain very much material on service provision. Contact him at Thames Polytechnic London, Avery Hill Campus, Mansion Site, Bexley Road, Eltham, London SE9 2PQ England.

