# Polio Survivors:
# Their Quality of Life

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# Abstract

The history of poliomyelitis can be traced from an Egyptian mummy, 3700 B.C., to the present. We are still learning more about the disease. Polio Survivors: Quality of Life reviews the researchers from Underwood to Sabin, and reveals the struggle to find a vaccine to control the disease.

President Roosevelt, the most famous polio survivor, established the National Foundation for Infantile Paralyis March of Dimes to provide training, care and research. The Foundation supported sixteen respiratory centers across the country, provided equipment and respirators, and raised funds for research. When the vaccine became a reality, the focus of their efforts changed.

The Post-Polio Questionnaire was created (1) to develop a list of polio survivors throughout the country, (2) to determine their needs, and (3) to start a referral service for physicians and health professionals. Seven hundred respondents used in this study validated the physical problems polio survivors are experiencing.

The Polio Information Center began the day the first questionnaire was mailed. This organization has established a computerized list of polio survivors, started a referral

list of physicians, and collaborated with the Texas Institute of Rehabilitation and Research and several other research organizations in mailing a questionnaire seeking medical history. Many polio survival groups have joined the Polio Information Center, indicating that networking across the country has begun.

A second questionnaire, "Polio Disabled Women and Marriage: The Quality of Life," was developed to determine the quality of life of polio survivors. The respondents agreed that women who had polio have the same problems as able-bodied women, the same involvements and the same family relationships.

Two International Conferences on Post-Polio were held. The first, in Chicago, was informational, and the second, in St. Louis, was controversial. Physicians and people who had polio disagreed on every issue.

At present, the global incidence of new polio cases is probably 500,000 annually, indicating a need for better public health control.

> The turn of the twentieth century and the flowering of scientific medicine brought a new point of view, an era of sudden and incredible hope that something might be done after all. This hope soon ripened into eager optimism. By the 1940s and 1950s the compassion and interest of the American people and indeed of the world had been aroused to such a pitch that in a scientific age of almost unbelievable accomplishments it seemed possible that infantile paralysis might actually be conquered at last. As the crusade heightened, the world looked on expectantly. (Paul, 1971, P. 145)

# Chapter I

Controversy is the thread that runs through the story of polio--in the methods of treatment, and in the development of the vaccines. Changing philosophies, technological developments and the spirit of the times have all had their impact and all have reflected different points of view about poliomyelitis.

Interest in poliomyelitis has been renewed after thirty years. The disease which people remember, but do not speak about, is being discussed again by physicians and people who had polio. In the twentieth century, over 600,000 people in the United States had paralytic polio, more than half of them during the epidemics of 1947 to 1956. It is estimated that today there are approximately 250,000 polio survivors in this country. Many of these individuals had polio before official reporting became mandatory (Landauer, 1958).

## Introduction

During the past few years, polio survivors developed physical problems which possibly could be connected to the polio they had twenty-five to thirty years before. The original thought that polio was finished at the end of the acute stage seemed to need rethinking.

One day in August, 1980, a young women who was a delegate to the President's Committee on the Employment of the Handicapped boarded an intra-state plane in southern Illinois. The temperature on the ground hovered in the high 90s and there was little relief from the heat in the cabin of the plane.

She began having difficulty breathing before the plane took off and, since there was no stewardess aboard, she went to the pilot and asked for oxygen. He laughed and asked if she was the pregnant lady aboard. She explained that she was not, but she was experiencing acute distress. He told her there were no oxygen tanks available for passengers.

During the forty-minute flight, her anxiety increased as she was unable to catch her breath, felt faint, and experienced extreme dizziness. The pilot, not recognizing her problem, failed to call ahead for an ambulance or paramedic.

When her fiance met the plane, he immediately called for help. A paramedic at the airport administered oxygen, but the young woman was too weak to inhale it.

At the hospital, she was admitted directly to the Intensive Care Unit, where she was fortunate enough to have a physician who recognized her as a polio survivor in acute respiratory distress. She remained in the hospital for several weeks. The story spread by word of mouth to friends who were disabled activists, many of whom were polio survivors experiencing similar problems.

Within the next few months, two people in California died, one in Texas, and another in Washington, D.C. None of them had reached their fortieth birthday (Weiner, Note 1).

What was happening to people who had polio who had been stabilized for twenty-five to thirty years? What was eluding physicians who were unable to effectively treat symptoms? Why would people in the United States be concerned about poliomyelitis, a disease that had been controlled for thirty years?

This paper is a discussion of the history, the research, and the investigation into the quality of life of polio survivors.

## Literature Review

By looking at the Reader's Guide to Periodical Literature from 1945 to 1980 under the headings of both Infantile Paralysis and National Foundation for Infantile Paralysis, the history of poliomyelitis is revealed. It is fraught with controversy--in prevention, methods of treatment, types of vaccines to be used, and opinions of the survivors of polio.

The controversy which is so much a part of the past and present of polio continues to show itself in the most recent publications and in the two International Conferences on Post-Polio in 1981 and 1983. Robert Gorski points out the controversy in Disabled U.S.A. in two recent articles, "Post-Polio Syndrome: With What are we Dealing" (1982), and, "Is Your Syndrome My Aging?" (1983). He describes the never-ending confrontation between polio survivors and their peers who differ on the question of aging versus syndrome. Health professionals and physicians openly and publicly clash in their viewpoints regarding not just aging versus polio syndrome, but methods of treatment and the benefits of such treatment.

Both the Rehabilitation Gazette (1982), and the Proceedings of the First International Conference on

Post-Polio (1982), presented the medical difficulties some polio survivors are experiencing. Validated by some of the participants attending the conference, and unrecognized by others, it was decided by the conference participants that yes, there is an aging process in which all individuals participate, and yes, there appears to be a Post-Polio Syndrome, but very little is known about it.

Achievement (1982), from North Miami, Florida, and The Advocate (1983), from Winnipeg, Manitoba, Canada, newsletters for people with disabilities, agree that there is a Post-Polio syndrome and agree with the controversy about aging.

It is interesting that in 1981 and in 1982, major articles were written about the outstanding individuals connected with polio. Victor Cohn, in his article "Sister Kenny's Fierce Fight for Better Polio Care," (Smithsonian, 1981), presents yet another controversial polio issue with Kenny's development of a new treatment mostly unacceptable to physicians at that time. Movement versus rigidity (casting) were opposite sides of treatment until the March of Dimes officially sanctioned the Kenny method.

Hugh Gallagher, an historian especially interested in Franklin Delano Roosevelt, wrote "F.D.R., An Unusual Look at a Hero" in Disabled U.S.A. (1982). Although Roosevelt's political and international capabilities are well known, few knew the extent of his disability after polio because he was able to keep it well-hidden with the help of his sons and secret servicemen. Gallagher reveals in his article that the president firmly believed that the leader of the American people should be on his feet, or not appear disabled. Joseph P. Lash, author of _Eleanor and Franklin_ (1971), and the 1946 Georgia _Warm Springs Foundation Report_ each tell part of the story of President Roosevelt.

_Total Rehabilitation_, by George Nelson Wright, Ph.D. (1980), provided the necessary background to understand that the plight of Franklin D. Roosevelt led the way for the Office of Vocational Rehabilitation (OVR) to move from its original goal of taking care of disabled children to expanding services to young disabled veterans returning from World War II, and, then, to polio survivors--both children and young adults--who needed their assistance with training for employment to return to the community .

Kenneth Landauer, M.D., March of Dimes physician, published "An Analysis of Residual Disabilities (Paralysis and Crippling) Among 100,000 Poliomyelitis Patients: With Special Reference to the Rehabilitation of Postpoliomyelitis Patients" (1958), which was read at the Thirty-fifth Annual Session of the American Congress of

Physical Medicine and Rehabilitation, Los Angeles, California, in 1958. It provides basic understanding of the physical difficulties one encounters after polio.

"Respiratory Polio Rehabilitation in Manitoba," by Patricia Kaufert, M.D. and Joseph Kaufert, Ph.D., was published in Winnipeg, Canada (1980) over 25 years after the devastating epidemic there in 1952. The paper analyzes the 1952 polio epidemic and outlines new methods and practices of rehabilitation which could be applied to any disease category. It also discloses the stress felt by the individual and the needs of the hospitals during the 1952 epidemic and has led to an intensive study of more than 100,000 polio survivors in Canada.

Papers, correspondence and notes taken at the two International Conferences on Post-Polio supplied the basic information necessary to report on these events. The conferences, Chicago, 1981 and St. Louis, 1983, were both informational and controversial in content, presenters, resolutions and future goals. "What Ever Happened to the Polio Patient?" (1981), a booklet, was a reminder of the agenda, the presenters and their subjects. The first international conference on poliomyelitis since 1962, it was a forum for presenting data on the unexplained physical difficulties so many polio survivors are experiencing...interrupted sleep, pain, dizziness, fatigue, gastro-intestinal problems.

Simi Kelley Linton, in her paper, "Sexual Adjustment Following Spinal Cord Injury as a Function of Locus of Control" (1982), provided insight into the rehabilitation experience and sexuality. She presented credible statistics. Roberta B. Treischmann, Ph.D. presented "The Psychological, Social, and Vocational Adjustment in Spinal Cord Injury: A Strategy for Future Research" (1978), to address future planning for spinal cord injured individuals.

"Paraplegia does not seriously impair marital functioning" stated Kathleen Shea Abrams, in "The Impact on Marriages of Adult-Onset Paraplegia" (1981, p. 253). This review focuses on marital stability, sexual interaction and marital satisfaction.

"Premarital Counseling and the Couple with Disabilities: A Review and Recommendations," by Mary Louise Bernardo, R.N. (1981), reviews premarital counseling and recommends counseling also with non-disabled individuals.

"How Happy are the Disabled Permitted to Be?" asks Reichardt Von Hartmut in _Schwestern Revue_, a German publication (1978). He concluded--as happy as anyone else.

_Help for the Handicapped Child_ (1972) and _Making it With a Disability_ (Note 2) by Florence Weiner, gave historical background on the National Foundation for Infantile Paralysis and this organization's services to date.

Vol. 23 of the Rehabilitation Gazette (1980) presented the plans for the First International Conference on Post-Polio, included the Post-Polio Questionnaire and several articles on the types of physical difficulties people who had polio were experiencing.

The weekly publication, Science News Letter, helped put together the pieces in the fight against poliomyelitis in the 1950s. In its columns, Physics, Biophysics, and Endocrinology, it published articles such as "Polio Vaccine Trials Planned" (1954); "Polio Danger for Babies" (1955) points out that babies, under five, and most likely to get paralytic polio should it strike, were being excluded from the first vaccination plans of the Salk vaccine. "Steps to Polio Conquest" and "Polio is Ancient Disease" both appeared April 16, 1955. "How Polio Attacks Body" (1950) and "USSR Seeks U.S. Polio Fighting Know-How" (1956) also appeared.

Interest in the eradication of poliomyelitis has continued despite the few cases reported yearly. During the battle that raged over live or dead virus vaccine, "Live Polio Vaccine: Debate Over Safety" appeared in October, 1976. It discusses the shortages of the vaccine, and the replacement of the Salk vaccine (killed virus) with the Sabin vaccine (live attenuated poliovirus vaccine).

Coverage about polio at one time permeated the popular press, with a flow of articles in major mass circulation publications such as Reader's Digest and the women's service magazines. In recent years, these articles have dropped off, although one popular magazine, Science Digest, reported in May, 1982, that a poliovirus was put together in a new way by genetic engineering techniques. The man-made poliovirus can be modified to induce direct mutations.

A review of the worldwide status of poliomyelitis to 1980 was presented in "Persistent Poliomyelitis," which appeared in Scientific American, October, 1980.

As indicated by J. R. Paul M.D., in his History of Poliomyelitis, which provided invaluable footnotes and references not usually available, polio existed long before the twentieth century. Paul credited Dr. Oskar Medin, "the grand old man of Swedish pediatrics," Sir Charles Bell and George Colmer, M.D., who wrote, "Paralysis in Teething Children" (1843). Dr. Mary Putnam Jacobi published the "Pathogeny of Infantile Paralysis" in 1873 and Maurice Brodie described the work of Landsteiner and the Biology Department at McGill University, in 1931.

Maurice Brodie, a scientist who developed a vaccine, wrote an extensive paper on the infectious and immunizing power of poliomyelitis. The research was conducted by the Bacteriology Department, McGill University, Toronto, Canada, and the paper was titled, "Fall of Infectivity and Immunizing Power of Poliomyelitis Tissue at Intervals after Complete Paralysis" (1931).

The New York Medical Record, in December, 1894, reported the first polio epidemic in America.

Epidemic Poliomyelitis, published by the New York Neurological Society in 1907, discussed the work of the Committee in isolating the poliovirus in the United States.

The results of Salk's work with killed virus vaccine were reported in The Journal of the American Medical Association (1953) and widely spread throughout the world in newspapers, magazines, bulletins and newsletters. Later, when Sabin introduced the live attenuated poliovirus vaccine, he published "Studies on the natural history of Poliomyelitis" in the Journal of Mt. Sinai Hospital (1944). His work was discussed in the World Health Organization bulletins.

The National Foundation for Infantile Paralysis, March of Dimes, supported polio victims for about twenty years and raised tremendous sums of money. P. J. Fisher, in The Polio

Story (1967), wrote that roughly $630 million had been raised, and the 1946 and 1947 Annual Report of the National Foundation for Infantile Paralysis, and the National Foundation news release of December, 1944, provided background along with President Roosevelt's famous reply to Basil O'Connor on the fight against polio. Psychiatrist Edward Strecker discussed the emotional growing process of children who had polio in The Management of Poliomyelitis: the Convalescent Stage (1949) and in The Treatment of Infantile Paralysis, written by Dr. Robert Lovett (1916), the earliest suggested treatment is described. In an effort to have Lovett's treatment mode continued, the U.S. Public Health Service issued Public Health Bulletin, No. 242 (1938).

On Death and Dying, by Elisabeth Kübler-Ross, M.D. (1969), added an extra dimension to the material.

A final search in the Index Medicus, which, alone, had more than 500 listings, revealed articles as recent as 1983 on the vaccines and the spread of poliomyelitis throughout the world, especially in the developing countries. R. N. Basu discusses the "Magnitude of (the) Problem of Poliomyelitis in India" (1981); Nicholas Ward, in "Poliomyelitis, a Review" (1983), compares statistics in the Third World countries; and Thomas and Jacob John, in "Is

Poliomyelitis a Serious Problem in Developing Countries?" (1982), report on poliomyelitis in India and Ghana.

Immunization control of paralytic poliomyelitis in subtropical and tropical countries presents a challenge in the 1980s. In these developing countries, where the major part of the population lives in poverty, and where shortage of food, inadequate housing, sanitary facilities and sewage disposal are the main causes of debility and poor health, advanced public health programs are badly needed. David A. Robinson discussed this in "Polio Vaccination, A Review of Strategies" (1981).

Interest in the vaccines and their development, administration, and impact continues. In 1973, Allan M. Brandt wrote "Polio, Politics, Publicity, and Duplicity: Ethical Aspects in the Development of the Salk Vaccine," of the time the Salk vaccine was being developed. And Joseph Melnick reviewed the successes and failures of the vaccines in "Poliomyelitis Vaccines: An Appraisal after 25 Years" (1979).

Neal Nathanson and John Martin covered "The Epidemiology of Poliomyelitis: Enigmas Surrounding its Appearance, Epidemicity and Disappearance" (1979) and the Immunization Advisory Committee printed its "Recommendations" in 1982.

Dr. Albert Sabin updated his views just before his retirement in his article "Vaccine Control of Poliomyelitis in the 1980s" (1982).

The St. Louis Globe-Democrat, May 9, 1983, reported,

> They may walk with canes, or crutches, or heavy braces or sit in wheelchairs. They may be confined to an iron lung or carry a respirator just to breathe. But, the world's disabled are an army on the march.

## Methodology

This study, Polio Survivors: Quality of Life, is divided into four sections.

Chapter I. The major issues of the polio story begin with the search for a vaccine to eliminate the disease and the identification of scientists who were responsible for the almost total eradication of polio.

A review of the services of the March of Dimes revealed the power of the organization to raise money and provide for polio survivors during the epidemic years as well as supporting respiratory centers and research.

Chapter II is the evaluation of the Post-Polio Questionnaire (1981), undertaken to determine the needs and problems which individuals who had polio are now experiencing. It was based on the replies of 700 respondents from across the United States. The questionnaire contains demographic items, inquiries about onset, treatment, weaning from the respirator, and present condition of health.

The First International Conference on Post-Polio: "What Ever Happened to the Polio Patient?" (1981), the first polio conference since the 1950s, is discussed.

The Polio Information Center (1981) was established from both the questionnaire results and the feelings expressing the need for such a center by the participants at the conference.

Chapter III is a discussion of the second questionnaire entitled "Polio-Disabled Women and Marriage: The Quality of Life" (1983). Questions are focused on three areas of family relationships: family interactions, community participation, and statistics. Some of the "Comments" from the questionnaire are presented and reviewed.

The Second International Conference, May 1983, on Post-Polio is reviewed.

The present state of the Polio Information Center is discussed.

Chapter IV is a general conclusion which brings together recommendations and planning for future strategy to improve the quality of life for polio survivors.

## History of Poliomyelitis

For more than three hundred years, scientists tried to define poliomyelitis. Today, we understand that poliomyelitis is a viral infection which can paralyze by attacking the nerve cells which control voluntary muscles. Paralytic effects are quite variable, depending upon the part of the nervous system attacked. High spinal paralysis affects the muscles of the chest and diaphragm directly and a respirator becomes necessary to take over breathing. Paralysis of the muscles for swallowing and speaking usually requires surgery to keep the airway open.

There are three major types of paralytic poliomyelitis:

Spinal poliomyelitis is the most common type and is caused by infection of the anterior horn cells of the spinal cord. Weakness of the limbs and paralysis occur and may either readily disappear or remain permanent.

The upper part of the spinal cord is responsible for the nerves which control breathing and when the virus attacks this area--respiratory poliomyelitis--mechanical assistance becomes necessary for breathing. Voluntary actions like breathing, coughing, sneezing or sniffing cannot be performed.

Talking and swallowing become difficult if the brain stem, just above the spinal cord, is affected. In _bulbar poliomyelitis_, accumulated secretions blocking the airway can cause suffocation. Surgical intervention, a tracheostomy, is usually necessary.

In more than two-thirds of the diagnosed cases, the individual recovers quickly with little or no muscle weakness. If the case is severe, the individual develops pain, muscle tenderness and stiff neck in addition to headache, fever, nausea and vomiting. Some people are attacked by all three types of poliomyelitis.

The history of polio begins as far back as ancient Egypt, where murals depicting people with the familiar crippling deformities of polio have been unearthed. Archeologists have dated an Egyptian skeleton of a man who probably had polio at 3700 B.C. (_Science Review_, 1958).

After the beginning of the twentieth century, and until the introduction of the Salk vaccine in 1955, there were severe epidemics in the United States. The paralyzing deformities the Egyptians recognized had made polio one of the most feared diseases of modern times. Added to the fear was the feeling of helplessness in stopping the disease, preventing the epidemics or curing the individual.

There were epidemics of polio in all parts of the country, but the great epidemics occurred between 1942 and 1956. In 1953, there were 35,592 cases reported (United States Public Health Service, 1956).

Michael Underwood, a British physician, first detected polio and, in 1789, asked other doctors to "pay attention to it," (Paul, 1971). The first recorded epidemic, four cases, was in England in 1835.

"This deserves to be inquired into," stated Sir Charles Bell, a distinguished British neurologist, when he wrote his famous Case 183 in "The Nervous System of the Human Body as Explained in a Series of Papers Read Before the Royal Society of London" (1894, p. 434-35). An outbreak of polio on the island of St. Helena, some time between 1830 and 1836, revealed that all of the children between three and five who had the epidemic fever were left with shortened limbs. Case 183, reported in 1836, was a milestone in the history of polio; physicians not only treated the disease, but recognized a situation that needed looking into. Charles Bell made the first recorded references to experiments on the spinal nerve roots (Paul, 1971).

In 1840, Dr. Jakob von Heine, a German orthopedic surgeon, clearly described polio as an acute virus. It was his understanding that symptoms of polio result from damaged or destroyed nerve cells.

The first "real (recorded) epidemic," 10 cases, was reported from Louisiana, the parish of West Feliciana, in the Fall of 1841, by George Colmer M.D. All of the people who had polio were under two years of age and the common cause appeared to be teething (Science News Letter, 1955). George Colmer's life was described by Dr. A. E. Casey of Birmingham, Alabama in "George Colmer and the Epidemiology of Poliomyelitis" (Southern Medical Journal, 1944). Colmer was born in London in 1807 but settled in Louisiana, where he was more than just a physician; he was justice of the peace, local newspaperman, and active in civic duties and real estate. His account of the Louisiana epidemic was reported in the local paper and recorded in his diary.

Another person in the field of polio, Dr. Karl Oskar Medin, later known as the "grand old man of Swedish pediatrics," was born near Stockholm in 1847. Known as a superb clinical teacher, he was concerned about community care for children and was chairman of the Stockholm Board of Health. He was a prominent pediatrician and clinician.

Dr. Medin's most important contribution was his comprehension of the clinical course of poliomyelitis. It had already been established that the spinal cord was the site of the usual pathological lesions, but Medin observed that, in the beginning, there was a systemic phase. He claimed that early, minor symptoms and signs such as slight fever and malaise signified a generalized process, which coincidentally and later was occasionally followed by serious damage to the central nervous system.

Medin's place in the history of poliomyelitis, together with the early work of Heine, resulted in the name Heine-Medin for the disease, but other physicians resented the proper name title when they, too, were facing epidemics of poliomyelitis.

Scandinavia was virtually the first place to witness the epidemic form of poliomyelitis in the nineteenth century. It may have been due to the sparse population or, because it was far north, the people may have had less immunity to the disease (Paul, 1971). Later, the first notable epidemic in the Western Hemisphere occurred in Vermont. ("A poliomyelitis epidemic occurred in Vermont, when 123 cases appeared in Rutland and Wallingford between June, 1894 and September 1, 1894." [New York Medical Record, 1894].) This was alarming, for, even today, the greater the distance from the equator, the less chance has poliomyelitis of being endemic.

In the 1870s, Mary Putnam Jacobi published a definitive report describing the pathogenesis of infantile paralysis. She proposed the idea that the paralysis and deformity were due to tiny microscopic destructive lesions within the gray matter of the spinal cord. This was a completely new concept (American Journal of Obstetrics, 1974-75).

Despite her superior skills and ability, Mary Putnam was controversial because she was a woman. Her special heroine and idol was Elizabeth Blackwell, the first woman to become a graduate M.D. in the United States. (In spite of tremendous opposition, Dr. Blackwell maintained a medical practice in New York City.) Originally unable to overcome the opposition to her attendance in medical school, Putnam attended pharmacy school and graduated in 1863. The following year, after an abbreviated training at the Women's Medical School of Philadelphia, she received her M.D. She realized her limitations when treating patients during the Civil War years and enrolled at the Sorbonne in 1866 to earn another medical degree. The studies of pathology and physiology aroused her interest. Ranvier, Cornil and

Vulpian were doing exciting work on the neuropathology of poliomyelitis and she worked with them.

After her return to New York in 1873, she began her practice of internal medicine and married Dr. Abraham Jacobi. Jacobi became the father and founder of American pediatrics.

Early attempts to find a vaccine against poliomyelitis provided material for future research.

In Austria, Drs. Karl Landsteiner and Erwin Popper successfully injected bacteriologically sterile material obtained from the spinal cord of a fatal human case into two monkeys. The Macaca rhesus monkey developed paralysis after a long incubation period, 17 days; the other monkey died but the spinal cord revealed extensive lesions closely resembling poliomyelitis lesions in humans. This gave future scientists an experimental animal to work on. Landsteiner and Popper suggested that poliomyelitis might be caused by an invisible virus which grew in living tissue cells such as water, milk and sewage. By the end of 1909, those involved in the microbiological world had accepted the viral etiology of poliomyelitis because of the correctness of the experiments and the exact reproduction of the disease (Brodie, 1931).

In 1907, the chairman of the New York Neurological Society appointed twelve distinguished physicians to study the polio epidemic of 1907 in New York City. That year, 750 cases were reported. However, there may have been many more unreported cases. Dr. Simon Flexner, who was director of the Rockefeller Institute for Medical Research, was one of those appointed. The committee was composed of the leading authorities in the country. This was the last time that neurologists were in the position of dominance in researching poliomyelitis in the United States. Study and treatment of the disease was gradually taken over by pediatricians, orthopedists, virologists, internists, physical medicine specialists and public health officials, with neurologists used only as consultants.

Epidemic Poliomyelitis in New York, 1907 was finally published in 1910, after the news that the microbial cause of poliomyelitis had been discovered. Flexner quickly revised an entire section of the study to include his work on the pathology in the monkey. Flexner's work had the same characteristics as that of Landsteiner and Popper in 1909, but he and Dr. Martha Wollstein had, in addition, successfully passed the virus strains from one monkey to another, reproducing the disease serially. This was the first time the poliovirus had been isolated in the United States.

Flexner failed to distinguish between experimental poliomyelitis in the monkey and the disease in man, which led to misinterpretations in his work. Too late, he realized that in different species of monkeys, the poliovirus reacted differently, and his error influenced thought at the Rockefeller Institute for over a generation (Flexner and Strauss, 1909).

In 1933, Dr. Maurice Brodie produced a polio vaccine in New York City. The vaccine was obtained from the spinal cords of rare Indian monkeys that had been infected with poliomyelitis. And in 1935, Brodie, Park and Kolmer tested a live virus vaccine, which caused many cases of polio, rather than immunizing against it.

Until 1939, the virus could only be transmitted to monkeys; that year, Dr. Charles Armstrong, of the U.S. Public Health Service, successfully transmitted the Lansing strain to eastern cotton rats and, later, to white mice.

Dr. John Enders, Yale graduate and member of the World War II Commission on Measles and Mumps of the Army Epidemiological Board, suggested that the mystery surrounding measles, mumps and poliovirus could be solved faster by investigating them in children rather than adults. Working with a live virus strain, he revolutionized the study of infantile paralysis (Paul, 1971).

At the Second International Conference on Poliomyelitis in Copenhagen, held in September, 1951, Dr. Dorothy Horstmann reported viremia in orally infected chimpanzees. It meant that small amounts of virus which invaded the blood could probably be overcome by antibodies before reaching the central nervous system. This was far different than the older theory that the virus slipped directly up the nose into the brain (Paul, 1971).

In 1950, J. R. Paul wrote:

> In the present state of our ignorance, it is questionable whether we know how to handle the situation at all. Apparently what is needed most in this disease is some means, not of partially eliminating the virus from a community, nor of quarantine, but of bolstering up the immunity of children. That is, we would combat poliomyelitis as we now combat smallpox, diphtheria, and whooping cough, by vaccination.
>
> Since no vaccine of this kind is now known, it is, of course, impossible to foretell exactly what the nature of such a preventive might be.
>
> Without attempting to comment on the chances for or against the development of such a vaccine, I believe it is valid to say that this is the great quest to which the energy of many laboratories is being turned. The path is dangerous and difficult. (p. 389)

Key developments which brought the vaccine closer were the live virus research, the three antigenic types, and experimentation using chimpanzees. After World War II, when the Articles of the Nuremburg Tribunal were adopted, criteria for the use of human subjects for medical trials were revised. The use of volunteers was reviewed from moral, legal, and ethical standpoints. The traditional image of the physician was at stake.

A graduate of New York Medical College, Jonas Salk had also studied biochemistry, before he joined New York University's Department of Bacteriology. In 1947, he became an associate professor at the University of Pittsburgh. Salk, who favored a killed virus vaccine, utilized large numbers of volunteers, including children, in his early experiments. He reported his results at a meeting in Hershey, Pennsylvania, in January, 1953. Later, in March, 1953, his results were published in the Journal of the American Medical Association, but the Vaccine Advisory Committee was cautious. They wondered, since they favored Salk's inactivated vaccine, if the National Foundation for Infantile Paralysis would consider the live attenuated vaccine.

Immediately after the Korean War, the World Health Organization's Expert Committee on Poliomyelitis met in Rome. Because they had been viewed scientifically, politically, and academically, reports had an authoritative ring. Shortly after the nationwide vaccination program, several children came down with poliomyelitis and, after careful investigation, it was found that certain lots of the vaccine contained live poliovirus, which caused the disease. This certainly was a reminder of the tragic live-virus vaccines of Brodie, Park and Kolmer in 1935. The vaccine-associated cases appeared to be limited to California and Idaho where the lots of vaccine had been made by Cutter Laboratories; all vaccine made by Cutter was withdrawn from use. The confidence of the nation was shaken but the immunization program was not called off.

Jonas Salk introduced the first successful polio vaccine in 1955-1956. The three major breakthroughs which enabled him to develop the vaccine were: (a) the discovery of three strains of polio virus, the discovery that being attacked by one strain does not immunize against the others, and the use of all three strains in his vaccine; (b) the discovery that the polio virus circulates in the blood briefly before the onset of the illness; and (c) the successful isolation of the virus and growing it on tissue culture on non-nervous tissue cells, making live animals no longer necessary for research (<u>Science News Letter</u>, 1955). The Salk vaccine gave a promise of life-long protection. It had triple good news; it worked and it was safe, it was extremely effective against bulbar polio and it protected against family exposure (<u>Science News Letter</u>, 1955).

Administered by parenteral injection, preferably in infancy, the vaccine greatly reduced the number of cases of polio. After its introduction in 1955, and as it became available to the general public, polio was virtually eradicated.

In addition to the work on inactivated vaccine during the 1950s, a renewed interest in live virus immunization was taking place. Immunization by modified (attenuated) poliovirus, which still retained the power to create infection, had been discussed since the 1920s. Although the National Foundation had committed itself completely to the inactivated Salk vaccine, Dr. Albert Sabin presented his findings to the Immunization Committee in 1953.

Albert Sabin came to America from Poland, when he was fifteen, and attended New York University, first as a dental student and later transfering to the College of Medicine.

As a research assistant in the Department of Bacteriology, he was exposed to the urgencies and pressures of the polio epidemic of 1931. By 1939, Sabin was an associate professor of pediatrics in the College of Medicine at the University of Cincinnati. Before he entered World War II, in 1942, Sabin had concluded that:

> If virulent poliovirus entered by way of the mouth to initiate an infection in the alimentary tract that usually remained inapparent, then an orally administered attenuated poliovirus vaccine that caused an inapparent infection might be as effective as an injected inactivated vaccine in inducing immunity. (1944, p. 447)

(In 1955, Dr. Harold Faber, Stanford University School of Medicine, ascertained that the polio infection develops by a process of evolution, and that the polio virus enters the mouth rather than by nose or by air [Science News Letter, 1955].)

By the 1950s, Sabin was an authority on killed and live vaccines. During the years when the inactivated Salk type vaccine was being administered successfully in the United States, Sabin continued his experiments. His preliminary studies involved tests on thousands of monkeys, hundreds of chimpanzees and hundreds of adult volunteers.

The controversy over the use of inactivated vaccines and live virus vaccines continued. It was evident that inactivated vaccine stimulated antibody production and provided immunity sufficient to protect from poliomyelitis, but this immunity was not quickly induced or always long-lasting. Revaccination was necessary, especially with very young children (Salk). In contrast, after the ingestion of the live virus vaccine (Sabin), and as a result of actual infection, circulating antibodies were induced and there appeared local resistance in the intestinal tract. Because of the speed with which immunity was achieved, the live virus could be used effectively, and quickly, in the face of an impending epidemic or even in the middle of one.

The World Health Organization (WHO), at a special meeting of its Expert Committee on Poliomyelitis (1957) set up guidelines for field trials under careful controls. By 1958-1959, twenty field trials were being conducted using Sabin vaccine and two other types also being developed (by Koprowski and by Cox-Lederle).

After three more international conferences were held--one sponsored by the Sister Elizabeth Kenny Foundation of Minneapolis, two of them financed, and all under the auspices of the Pan American Health Organization (PAHO)--and four years of deliberations, the live virus vaccine was finally given to the medical profession for general use.

## Comparison of Live and Killed Polio Vaccine

The following comparisons of live and killed polio vaccine are from "Poliomyelitis Vaccines: An Appraisal After 25 Years" (Melnick, 1980).

### Live Polio Vaccine: Advantages

1. Confers both humoral and intestinal immunity; like natural infection.

2. Immunity induced may be lifelong.

3. Induces antibody very quickly in a large proportion of vaccines.

4. Oral administration is more acceptable to vaccines than injection, and is easier to accomplish.

5. Administration does not require use of highly trained personnel.

6. When stabilized, can retain potency under difficult field conditions with little refrigeration and no freezers.

7. Under epidemic conditions, not only induces antibody quickly but also rapidly infects the alimentary tract, blocking spread of the epidemic virus.

8. Is relatively inexpensive, both to produce the vaccine itself and to administer it, and does not require continued booster doses.

9. Can be prepared in human cells, thus is not dependent on continuing large supplies of scarce monkeys (this also eliminates theoretical risk of including monkey virus contaminants in the vaccine).

Live Polio Vaccine: Disadvantages

1. Being living viruses, the vaccine viruses do mutate, and in rare instances have reverted toward neurovirulence sufficiently to cause paralytic polio in recipients or their contacts.

2. Vaccine progeny virus spreads to household contacts.

3. Vaccine progeny virus also spreads to persons in the community who have not agreed to be vaccinated.

4. In certain warm-climate countries, induction of antibodies in a satisfactorily high proportion of vaccinees has been difficult to accomplish unless repeated doses are administered. In some areas, even repeated administration has not been effective.

5. Contraindicated in those with immunodeficiency diseases, and in their household associates, as well as in persons undergoing immunosuppressive therapy.

Killed Polio Vaccine: Advantages

1. Confers humoral immunity in satisfactory proportion of vaccines if sufficient numbers of doses are given.

2. Can be incorporated into regular pediatric immunization with other vaccines (DPT).

3. Absence of living viruses excludes potential for mutation and reversion to virulence.

4. Absence of living virus permits use in immunodeficient or immuno-suppressed individuals and their households.

5. Appears to have greatly reduced the spread of poliomyelitis in small countries where it has been properly used (wide and frequent coverage).

6. May prove especially useful in certain tropical areas where live vaccine has failed to "take" in young infants.

Killed Polio Vaccine: Disadvantages

1. Several studies have indicated a disappointing record in percentage of vaccines developing antibody after three doses.

2. Generally, repeated boosters have been required to maintain detectable antibody levels.

3. Does not induce local (intestinal) immunity in the vaccines. Hence vaccines do not serve as a block to infection with wild polioviruses.

4. More costly than live vaccine, in single dose cost, administration expense, and total amount required, including boosters.

5. Subject to problems from present and growing scarcity of monkeys (but could be resolved if high-titer virus could be grown in human diploid cells and shown, in field tests with adequate numbers of persons, to be free of any problems resulting from injection of virus grown in human cells).

6. Use of antigenically potent but virulent polio viruses as vaccine seed creates potential for tragedy if a single failure in virus inactivation were to occur in a batch of released vaccine.

## Rehabilitation: Organizations, Foundations

Sister Elizabeth Kenny, a simple country women who bought a nurse's uniform and talked her way into the Australian Army Nurses Service during World War I, created enormous controversy when she developed a treatment which revolutionized polio care.

In 1911, when Sister Kenny was told there was no known treatment for infantile paralysis, she treated a two-year-old child with strips of blanket soaked in boiling water, wrung out, and applied to the afflicted limbs. Ignorant of textbook warnings, she moved the child's relaxed limbs in normal patterns.

Infantile paralysis was still a new disease in 1911. A plague of civilization, it is caused by a virus so common that in primitive societies, there was wide, mild and unnoticed childhood infection, then immunity. With sanitation, the polio virus began hitting harder and harder. At the beginning of the century, it was just striking forth. The methods of treatment were still unresolved.

Physicians believed that during the acute stages of polio, muscles which were flaccid and pulled out of shape by adjoining, stronger muscles, must be held straight, often by casting. Muscles might atrophy, but they could be supported later, they felt, by braces. It became evident that it would take someone with a vigorous personality to convince the system that casting--keeping paralyzed limbs immobile--could be harmful. Sister Kenny contended that there was no time to lose, that she could intervene by moving the limb after heat was applied, the pain relieved, and the muscle spasms and tightness relaxed.

But, it was Dr. Robert Lovett of Boston whose book _The Treatment of Infantile Paralysis_ (1916) had brought to the world a description of the stages of the disease: the acute stage, which persisted until muscle tenderness disappeared, was treated by bed rest, physical therapy, warm baths and prevention of deformities. The convalescent stage was to restore muscles to maximum function by not splinting, cautious movement, massage, heat and electricity. The chronic stage was for corrective surgery, exercise and improvement of muscle power.

Twenty years later, Lovett's views had been distorted and during the 1930s, early and prolonged splinting was carried to excess, in spite of the effort of the U.S. Public Health Service to combat this practice (Public Health

Bulletin, 1938). By 1940, it had become obvious that early immobilization had gone too far.

After limited success in Australia, and after battling the medical establishment for years, Kenny was acknowledged as having made an important contribution. She arrived in America in April 1940 at just the right time. Every summer was polio season and frightened parents kept children at home. Dr. Kristian G. Hansson, Cornell Medical College, related that no specific treatment existed for acute polio and in the face of epidemics there was helplessness.

Sister Kenny, seeing children straightened under anesthetic, placed in casts, and immobilized, was convinced that most of the problems of polio were not caused by cell-death and irreversible paralysis, although there were some, but by three phenomena:

1. Spasm, muscle tightness and shortening causing pain and tension, distorting the skeleton.

2. Mental alienation, inability to move a muscle even though nerve paths were intact.

3. Incoordination, reliance on the wrong muscles.

Sister Kenny repeatedly offered her help and training in her technique, but she was turned down. When Basil O'Connor (president, National Foundation for Infantile

Paralysis) declared the Kenny treatment was superior, the Journal of the American Medical Association endorsed the new method. All over the country, doctors started switching to the Kenny treatment method.

The City of Minneapolis established an Elizabeth Kenny Clinic, still operating today as the Sister Kenny Institute, a comprehensive rehabilitation center. In 1950, a Joint Congressional resolution gave her the first visa-free passage across United States borders granted to any foreign visitor since Lafayette.

Sister Kenny was again fighting physicians for using a new "modified method" which she regarded as inferior. She broke with Basil O'Connor, began her own Kenny Foundation, and opened more clinics.

The public, especially women, backed her. With the support of Eleanor Roosevelt, first lady of the country, Sister Kenny helped women move to a new era of power and authority. Ironically, Sister Kenny developed a neuromuscular disease, Parkinson's Disease, in 1951, and retired to Australia where she died of a stroke in 1952.

The Smithsonian's curator of medical history, Dr. Audrey B. Davis, described Sister Kenny as "a major twentieth century medical empiricist who successfully brought her effective techniques into the arsenal of medical theorists." (Smithsonian, 1981, p. 200)

Without a doubt, the most famous polio survivor was Franklin Delano Roosevelt, President of the United States from 1932 to 1945. Polio left President Roosevelt with the use of his upper extremities only. He could propel himself rapidly around a room in a specially designed dining room chair with attached wheels. Full braces allowed him to stand and walk a few steps, and it was not unusual to see him driving a hand-controlled convertible around Hyde Park. He was rarely photographed in a wheelchair and when he was sworn in as President, he managed, with extreme difficulty, to stand for the swearing in ceremony (Lash, 1971).

In 1927, he established the Georgia Warm Springs Foundation. Having found the water springing from Pine Mountain, Georgia beneficial, he gave the foundation his 27,000 acre farm in order to help others who had the disease. The Little White House, where he died in 1945, was the cottage he retained for his personal use and where he returned frequently.

The purpose of the Warm Springs Foundation was twofold: First, to give direct aid to patients through the skill of an able, carefully selected professional staff, in a place with agreeable surroundings and natural warm water; and, second, to pass on to hospitals and the medical profession useful observations or special methods of proved merit, resulting from this specialized work, which might be suitable for practical application elsewhere.

Warm Springs became the leading rehabilitation hospital in the country for "aftercare" of poliomyelitis patients (Annual Report, Georgia Warm Springs Foundation, 1946).

Roosevelt's election to the presidency gave a tremendous boost to the cause of poliomyelitis and established him as a symbol of hope and courage. Roosevelt's birthday, January 30th, was chosen as the date for a nationwide subscription ball to aid the Georgia Warm Springs Foundation.

Within several years, the PBBC--President's Birthday Ball Commission--was succeeded by the National Foundation for Infantile Paralysis. (The charity ball had become inappropriately named "Paralysis Dance".) The National Foundation for Infantile Paralysis (NFIP), established in 1938, had Basil O'Connor, a former law partner of Roosevelt's, as its president.

The constant claims during the 1930s that "breakthroughs were just around the corner" brought money into the NFIP, enabling it to set up a program dealing with individual aspects of the disease. The public picture of poliomyelitis had been transformed by 1940, from its medical and public health image to one that had more sentimental--or psychosocial--appeal (Annual Report, NFIP, 1943).

The aims of the NFIP (Sills, 1957) were:

1. Making sure that no polio patient--man, woman or child--shall go without the best available medical care for lack of funds.

2. Informing the public about the disease, methods of dealing with it and of the activities and goals of the National Foundation.

3. Raising sufficient funds through the March of Dimes to finance adequately the National Foundation's program of research, professional education, patient care, and polio prevention.

The effective use of marketing techniques brought about public interest in poliomyelitis research similar to a "holy quest," a national mission. The image of polio as an evil thing to be conquered and banished took hold and a financial contribution seemed to be a legitimate way to help. The American people crusaded against polio for twenty years and raised roughly $630 million (Fisher, 1967).

Dr. Thomas M. Rivers, American virologist, became chairman of the Foundation's Committee on Scientific Research. He realized he needed a solid science team to accomplish Basil O'Connor's goal to conquer polio. The first meeting held in 1938 dealt with definition of issues: What is poliomyelitis--is it clearly defined? Does more than one form of the virus exist, and, if so, are the forms separable and idenfitiable?

Although the prevention of poliomyelitis had been relentlessly pursued since the discovery of the virus, there was still a long way to go. As the Foundation gained experience and grew in size, its credibility increased: It supplied financial support for increased research for the development of a vaccine against poliomyelitis; it backed a cooperative virus typing program between laboratories, which resulted in the separation of the polioviruses into three types; it became a bureau of health education; it supplied public and professional information as to what to do if polio struck; and it provided courses for physical therapists and information to physicians, pediatricians, and orthopedic surgeons on respirators and orthopedic techniques (Annual Report, NFIP, 1946).

In a letter to President Roosevelt, O'Connor wrote on November 27, 1944 that "unremitting research will provide the key which will unlock the door to victory over infantile paralysis" (NFIP News Release, Dec. 8, 1944). Four months before his death, in the closing year of World War II, Roosevelt replied:

> We face formidable enemies at home and abroad. Victory is achieved only at great cost--but victory is imperative on all fronts. Not until we have removed the shadow of the Crippler from the future of every child can we furl the flags of battle and still the trumpets of attack. The fight against infantile paralysis is a fight to the finish, and the terms are unconditional surrender. (NFIP News Release, Dec. 8, 1944)

In July, 1948, the First International Poliomyelitis Conference was held in New York City. Every three years afterwards, until 1962, an international conference was held by the National Foundation for Infantile Paralysis. The five international conferences made scientific information available immediately around the world and discussions on tissue-culture methods, diagnostic tests, viremia, types of vaccine contributed to methods used today.

Two other organizations, the European Association Against Poliomyelitis and Allied Diseases, founded in 1948, and the World Health Organization, were formed to help in the collection, dissemination and standardization of medical information, and were accepted universally.

At the First International Poliomyelitis Conference, New York, 1948, Edward Strecker, M.D., a psychiatrist from Philadelphia, said:

> Polio is, of course, a major insult to developing personality, and notably to the ego of the child....It provides severe psychic temptations for the child, the mother and for the whole family. For the child, it offers the opportunity to thwart emotional maturing or to distort it very seriously...its disabling effects provide a splendid opportunity for the retention of the so-called power stage of the child....The problem psychiatrically is to set the stage for the child and for the family so that polio interferes as little as possible with the emotional growing process. (p. 337)

The March of Dimes was the fund-raising division of the National Foundation for Infantile Paralysis. The families, friends and neighbors of people who had polio were organized into neighborhood teams to collect dimes door-to-door on the evening of President Roosevelt's birthday. The March of Dimes was created to look for a cure for the thousands of children who every year became severely disabled. So the money poured in.

During the terror-ridden epidemic years, the March of Dimes spent over a quarter of a billion dollars on the rehabilitation needs of polio survivors. Sixteen respiratory rehabilitation centers were established across the country with sites chosen as a result of a report done by Dr. Kenneth Landauer, the March of Dimes physician (Landauer and Stickle, 1958).

Based in teaching hospitals which had medical school affiliation, the first two respiratory rehabilitation centers were in Boston and Houston. There were three centers in New York State: in Buffalo, at the University of Buffalo; at Mt. Sinai Hospital, in New York City; and at the Goldwater Memorial Hospital, Welfare Island (now Roosevelt Island), New York City (Landauer, 1958).

As the money poured into the March of Dimes, it, in turn, poured it into the centers. Opened in the 1950s and closed down in the early 1960s, the respirator centers had less than 500 beds nationwide, but served more than 4200 patients. The three-fold programs of research, teaching and service provided full-scale rehabilitation. These programs provided total medical care with teams having medical specialties and paramedical skills. The most hopelessly disabled patients known to medical science, quadriplegics with respiratory involvement, were treated. Many not only had their lives saved, but their lives were made worth living. The centers proved also that by providing physical, psychological, social and vocational rehabilitation, they could provide the best care at the cheapest cost. Severely disabled people were able to return to their communities and were given the support systems necessary for them to function within their new physical boundaries.

The National Foundation, March of Dimes, provided everything--respiratory equipment, financial assistance for attendants, wheelchairs, braces and even special bathtubs. Individuals, both in the hospital and at home, received the medical, psychological and vocational services needed without worrying about cost. There was something about the team spirit, about the March of Dimes, that touched everyone--patients, staff, families and volunteers.

## Additional Background Material

From the time multistate reporting began in this country, the U.S. Public Health Service reported a total of 572,360 cases of poliomyelitis between 1915 and 1956 (refer to Table 1 and Figure 1). Over half of all cases, 318,344, were reported between 1947 and 1956. After the Salk vaccine, 5,485 cases were reported in 1957 (refer to Figure 2). In 1974, 5 cases were reported to the Center for Disease Control (CDC) (refer to Table 2 and Figure 3).

Insert Table 1 and 2 about here

Insert Figures 1, 2 and 3 about here

According to Landauer (Archives of Physical Medicine and Rehabilitation, 1958), 45 percent of all cases of polio involve paralysis of both legs, with severe paralysis in 16 percent; involvement of both arms, 6 percent; quadriplegic or total paralysis, 1.5 percent; 15 percent of all individuals get respiratory involvement.

In the early epidemics, children under ten were most affected, but, after 1945, the occurrence appeared more with the young adults.

## Table 1

## Poliomyelitis Cases Reported in the United States

## 1915-1956

| Year | Number of Cases |
|---|---|
| 1915 | 1,639 |
| 1916 | 27,363 |
| 1917 | 4,174 |
| 1918 | 2,543 |
| 1919 | 1,967 |
| 1920 | 2,338 |
| 1921 | 6,301 |
| 1922 | 2,255 |
| 1923 | 3,489 |
| 1924 | 5,262 |
| 1925 | 6,104 |
| 1926 | 2,750 |
| 1927 | 10,533 |
| 1928 | 5,169 |
| 1929 | 2,882 |
| 1930 | 9,220 |
| 1931 | 15,872 |
| 1932 | 3,820 |
| 1933 | 5,043 |
| 1934 | 7,510 |
| 1935 | 10,839 |
| 1936 | 4,523 |
| 1937 | 9,514 |
| 1938 | 1,705 |
| 1939 | 7,343 |
| 1940 | 9,804 |
| 1941 | 9,086 |
| 1942 | 4,167 |
| 1943 | 12,450 |
| 1944 | 19,029 |
| 1945 | 13,624 |
| 1946 | 25,698 |
| 1947 | 10,827 |
| 1948 | 27,726 |
| 1949 | 42,033 |
| 1950 | 33,300 |
| 1951 | 28,386 |
| 1952 | 57,879 |
| 1953 | 35,592 |
| 1954 | 38,476 |
| 1955 | 28,985 |
| 1956 | 15,140 |
|  | 572,360 |

## Table 2

## Poliomyelitis Cases Reported in the United States

## 1957-1981

| Year | Number of Cases |
|---|---|
| 1957 | 5,485 |
| 1958 | 5,787 |
| 1959 | 8,425 |
| 1960 | 3,190 |
| 1961 | 1,312 |
| 1962 | 910 |
| 1963 | 449 |
| 1964 | 122 |
| 1965 | 72 |
| 1966 | 113 |
| 1967 | 41 |
| 1968 | 53 |
| 1969 | 18 |
| 1970 | 32 |
| 1971 | 20 |
| 1972 | 22 |
| 1973 | 15 |
| 1974 | 5 |
| 1975 | 14 |
| 1976 | 10 |
| 1977 | 20 |
| 1978 | 9 |
| 1979 | 22 |
| 1980 | 9 |
| 1981 | 7 |
|  | 26,162 |

Figure 1

Reported Poliomyelitis Cases

1915 - 1957

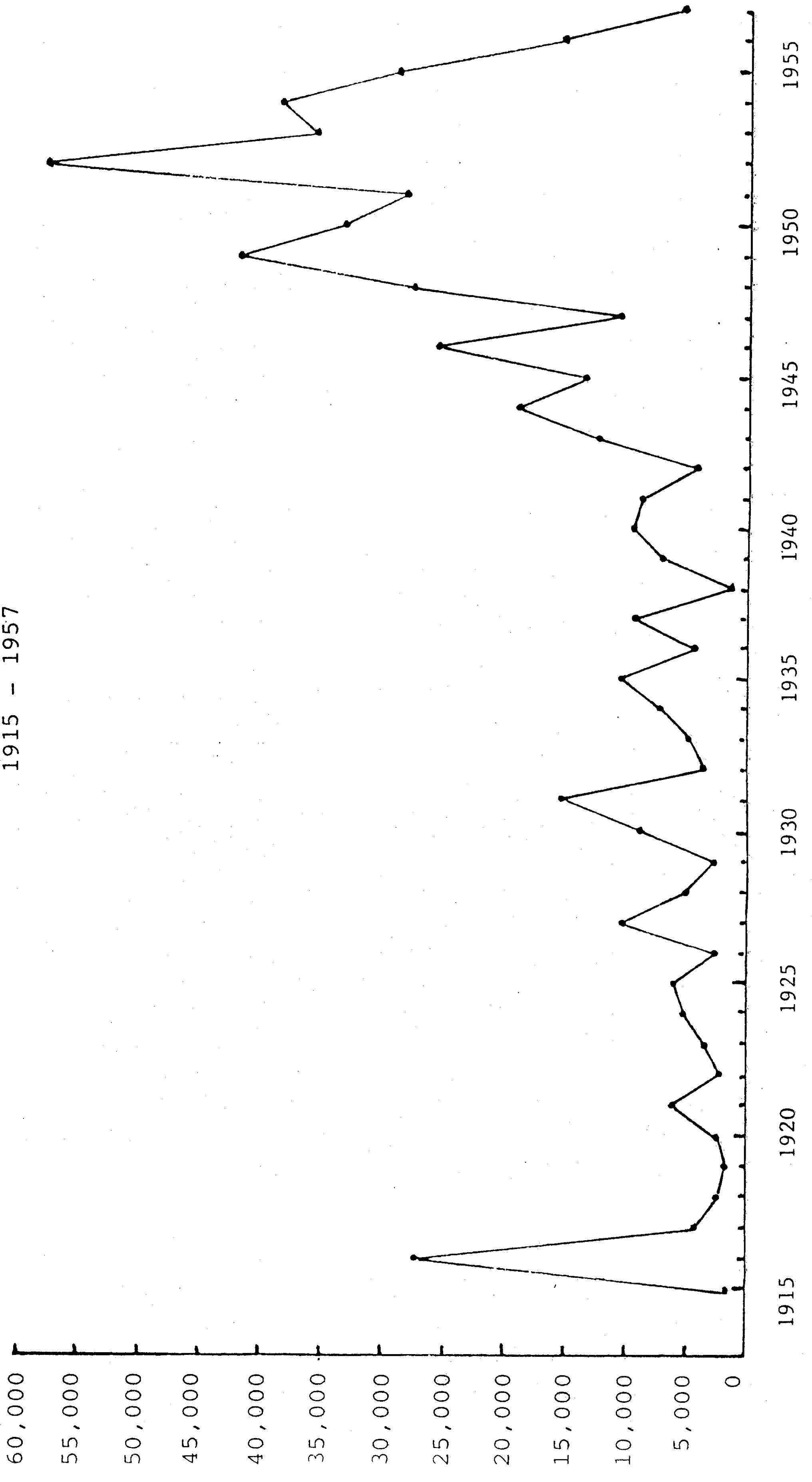


Figure 2

Reported Poliomyelitis Cases

1957 - 1968

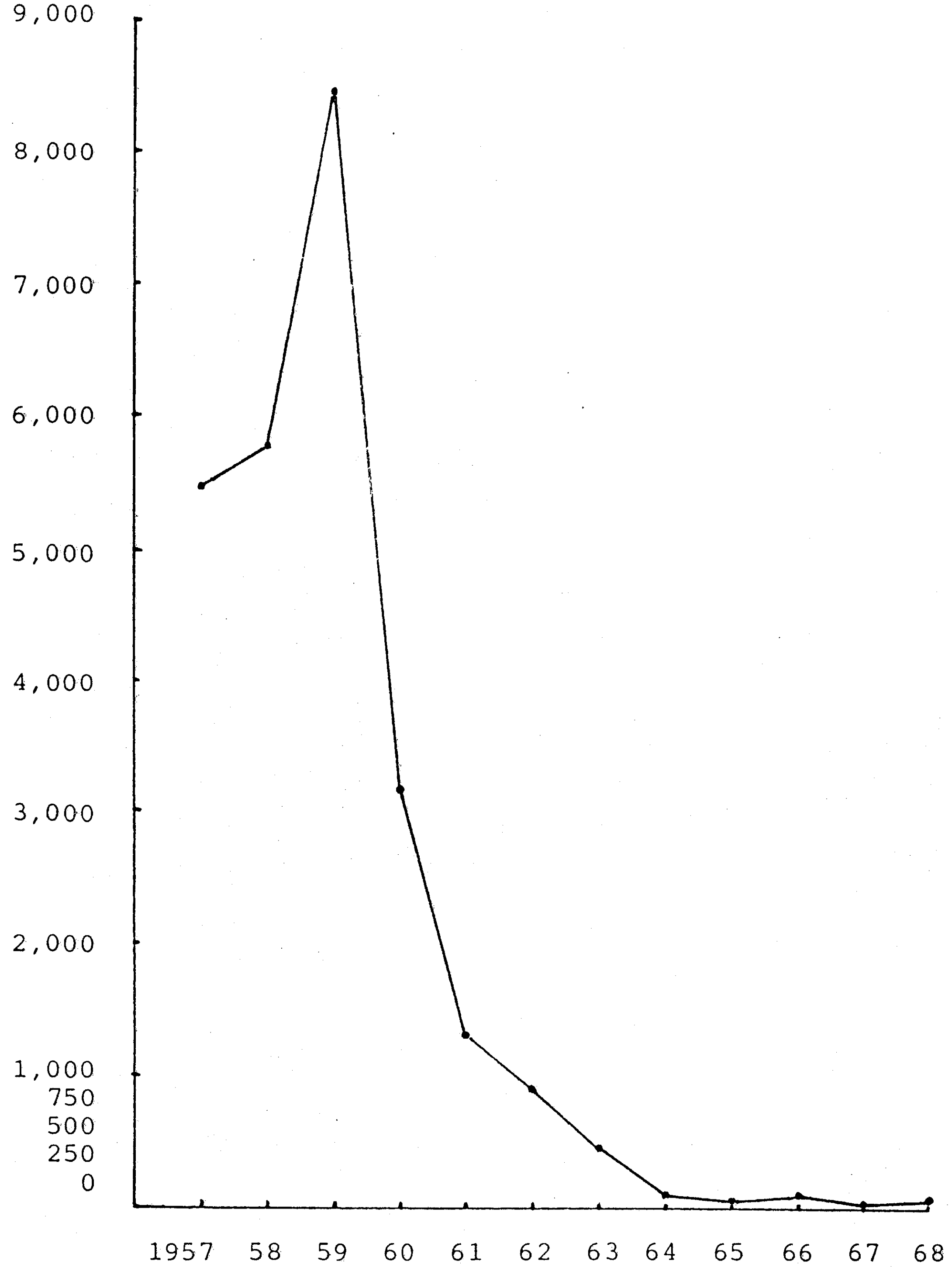
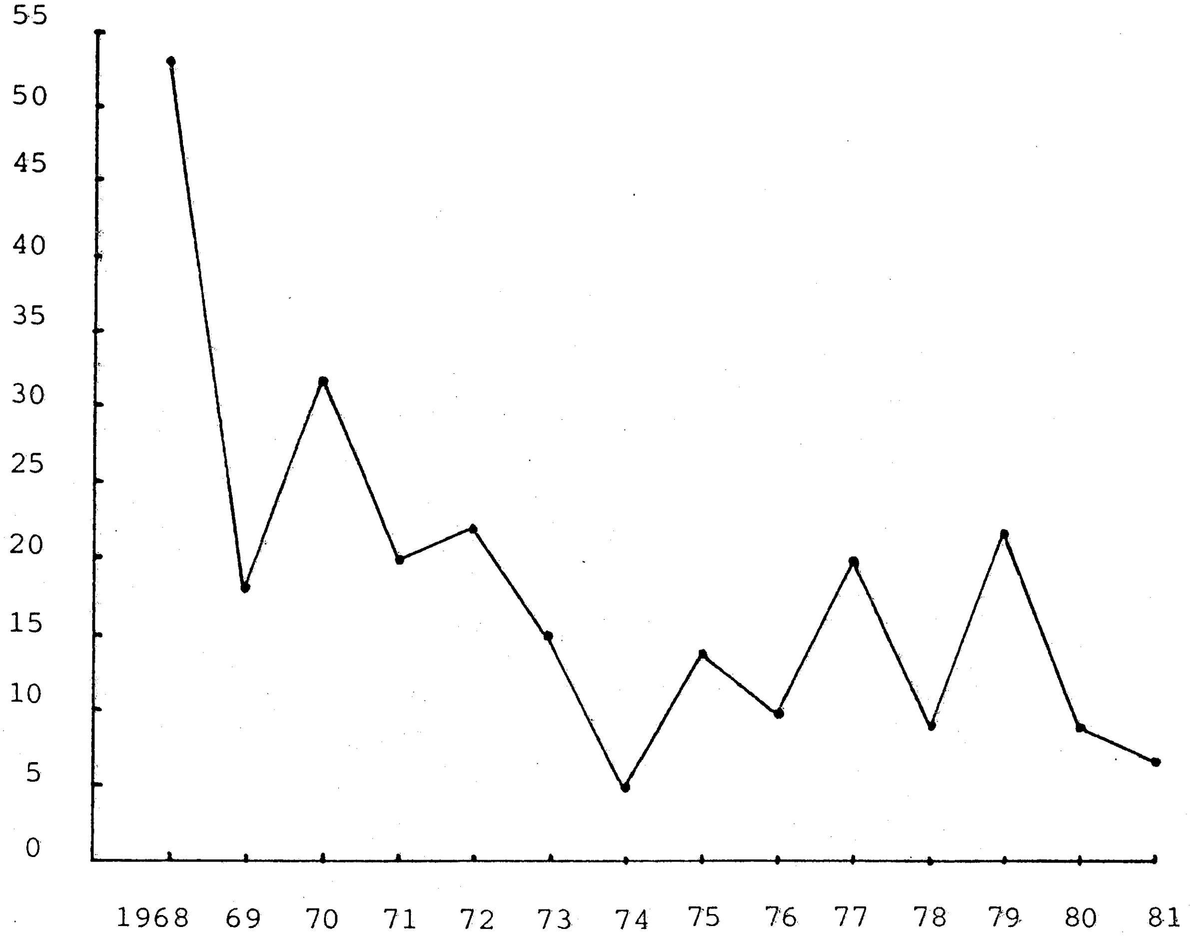


Figure 3

Reported Poliomyelitis Cases

1968 - 1981



Poliovirus has been discovered in various insects, cockroaches and flies, and from food contaminated by them; but, after decades of scientific investigation, there appears to be no host for polio other than man.

Poliomyelitis does not maintain any set patterns. It attacks those who seem to be in the best of health, pregnant women and very active individuals.

## Conclusions

Geographic areas make little difference. Polio has been recorded as far north as Iceland and Alaska as well as South America, Africa and India. But, it was mostly in temperate climate, in late summer or early fall, that the epidemics occurred (Paul, 1971).

During the first sixty years of the twentieth century, major epidemics occurred throughout the temperate, industrialized part of the world. Between 1950 and 1955, 85,000 cases of poliomyelitis were reported to the World Health Organization, 87 percent originating in Europe, Australia, North America and Japan. Since the introduction of the polio vaccines, the incidence of the disease rapidly declined in these countries, removing it as a major health problem in the world.

However, in developing countries, it appears that polio is still a serious public health problem. In India, vaccine is available only in urban areas and, as recently as 1979, the cases numbered 13,451 (Basu, 1981). The annual incidence of polio in Ghana is 232 per million population, or twice as high as it was in the United States before the vaccines were introduced (Ward, 1983).

Overall estimates put paralysis after all types of poliovirus vaccines at about one case per 9 million vaccinations and 2 cases per 9 million in contacts of vaccinated individuals (Report from the Committee, Amer. Acad. of Pediatrics, 1974).

Almost 42,000 cases of poliomyelitis were reported to the World Health Organization in 1980. This figure has remained nearly constant during the past ten years with changing trends in various areas which change numbers. Surveys show that routine reporting only identifies 5 to 10 percent of actual cases. The true global incidence is probably 500,000 annually (Ward, 1982). In view of the successes, if present trends continue, polio, in the future, may be a rare event.

The results of this paper can be used as a basis for research in the field of Post-Polio.

# Chapter II

## The Post-Polio Questionnaire

The Post-Polio Questionnaire was developed in the wake of renewed interest in--and mounting alarm over--the physical problems being experienced by polio survivors.

After many years of disinterest, awareness of the legacy of the major polio epidemics in the United States during the second quarter of the nineteenth century was again brought to the public. "Prime Time Saturday," NBC, July 5, 1980, was the first television program to address the physical problems that people who had polio many years before were experiencing. Symptoms such as fatique, interrupted sleep, pain and muscle weakness were mentioned. Three rehabilitation centers in this country were given as resource centers for additional information. Following the broadcast, these centers were inundated with mail and inquiries. The reply from the Warm Springs Georgia Foundation included the following paragraphs:

> "It has become apparent that some previous polio patients (we do not know the percentage affected) lose strength rapidly during middle age. The muscles most commonly affected are those that recovered well from the initial attack and have been used strenuously since. The majority of

those letters received from you have indicated this "mysterious" presentation of symptoms - (1) progressive weakness with/without pain, (2) involvement of areas not previously recognized as being affected. The age at which polio was contracted seems to have no relationship with time of onset of secondary loss or with degree of disability. Although symptoms may resemble more serious disorders, such as the Lou Gehrig disease, studies do not reveal any relationship to the problem presenting in polio patients.

"It is our opinion that fatigue is of primary importance in weakening of compromised muscles, and patients are urged to avoid overuse. Pain or a sense of muscle fatigue are indications of overuse and exercise should be discontinued when either appears. We have advised an adequate but limited exercise regimen designed to maintain that strength in previously involved muscles and avoid overloading (overexercising) those muscles which previously were not recognized as having been affected. Participation in competitive sports, jogging, and strenuous calisthenics should be avoided.

"It is recommended that patients who are experiencing symptoms of increasing weakness or muscle pain be examined to determine degree of impairment and have prescribed for them an individualized program of activity. Bracing or other supports should be accepted as needed to maintain function. We have secured a list of rehabilitation facilities where these services

> might be obtained, and suggest that one in your vicinity be contacted if need arises."

In an attempt to determine the needs and problems of individual polio survivors and to provide an ongoing resource information service, Harriet Bell and Florence Weiner designed the Post-Polio Questionnaire. Harriet Bell is a Health Advocate who has worked for patients' rights in municipal hospitals in New York City. She serves on several Boards at Goldwater Memorial Hospital where she was a patient for 25 years--Auxiliary, Friends of Goldwater, Community Board, and the Chaplaincy Advisory Board. She is a public member of the New York State Board for Nursing and member of the Professional Advisory Committee for Easter Seals, New York State.

Florence Weiner is an activist and advocate for the rights of disabled individuals. She serves on several Boards--American Coalition of Citizens with Disabilities and the League of Disabled Voters. She has published four books, the most recent being <u>Help for the Handicapped Child</u>. Another book is ready for publication. She is married to Richard Weiner; they have two children.

The Post-Polio Questionnaire was designed to locate polio survivors in the United States and develop a referral list of physicians and services. Out of this grew The Polio Information Center, Roosevelt Island, New York.

The Rehabilitation Gazette (1981) published the Post-Polio Questionnaire in April, six months before the First International Symposium on Post Polio--"What Ever Happened to the Polio Patient?"--which took place in October, 1981, in Chicago, Illinois.

Published by Gini and Joe Laurie of St. Louis, Missouri, The Rehabilitation Gazette is a highly respected publication for, and by, people with all types of disabilities. It was originally the newsletter for the Respirator-Rehabilitation center at Chagrin Falls, Ohio, and developed into a national publication. (In 1983, the Lauries received a special citation from President Reagan for their contributions to rehabilitation.)

The mailing list used by the Gazette is, according to its publishers, comprised of more than 6,000 names of people around the world; subscribers are primarily disabled individuals. The Post-Polio Questionnaire (see Addendum A) was mailed in the Gazette, with a perforated line indicating where the respondent could tear it off and return it to the Polio Information Center.

The initial response was poor; fewer than 100 completed questionnaires were returned. But, it was the beginning of a chain reaction which resulted in requests for additional questionnaires. These requested questionnaires were mailed out immediately. When more than 700 questionnaires had been completed and returned to the Polio Information Center, it was time to turn to a computer for help in handling the data.

Since the questionnaires were from all parts of the United States and, more important, were from all types of polio survivors --ambulatory, paraplegic and quadriplegic--the 700 questionnaires were considered to be a credible sampling of polio survivors in the United States.

Viewer response to the "Prime Time Saturday" broadcast, the large number of completed and returned questionnaires and a growing awareness that polio survivors were experiencing new physical problems, precipitated interest within the disability groups. Respondents verified the reality and severity of physical difficulties.

## Analysis of the Post-Polio Questionnaire

Four hundred and sixty four of the 700 respondents (62 percent) were women. Replies were received from all except six states, with the greatest number from California (124 [19 percent]), New York (89 [16 percent]) and Ohio (59 [9 percent]), indicating not only heavily populated areas, but probably the areas where the polio epidemics had been most severe. Very few completed questionnaires were received from the northwestern states--Idaho, Utah, North Dakota, South Dakota, Wyoming or Washington.

In addition, completed questionnaires were received from China, Canada, Puerto Rico, England and Australia.

Table 3 indicates the age of the survey respondents; the youngest was 25 and the oldest was 85. A total of 599 respondents are included in this table; 103 questionnaires did not include current age at time of survey. The accompanying bar graph (refer to Figure 4) indicates that people now aged 51, who were 21 years of age when they contracted polio, represent the largest age category.

Insert Table 3 about here

Table 3

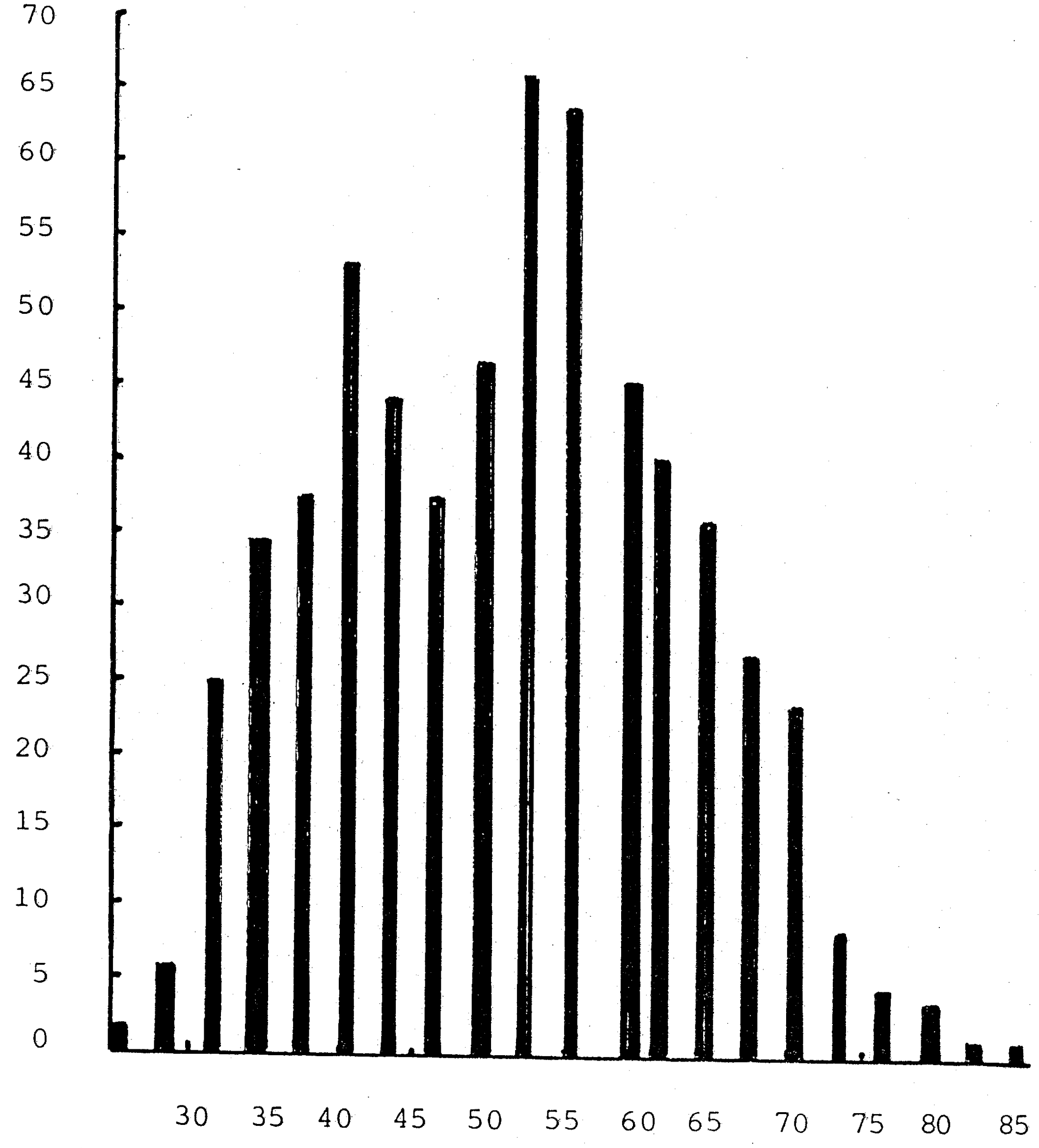
Age of Survey Respondents

| Age | Quantity |
|---|---|
| 25 | 2 |
| 28 | 6 |
| 31 | 25 |
| 34 | 34 |
| 34 | 37 |
| 40 | 53 |
| 43 | 44 |
| 46 | 37 |
| 49 | 46 |
| 52 | 66 |
| 55 | 64 |
| 58 | 45 |
| 61 | 39 |
| 64 | 35 |
| 67 | 26 |
| 70 | 23 |
| 73 | 8 |
| 76 | 4 |
| 79 | 3 |
| 82 | 1 |
| 85 | 1 |

Insert Figure 4 about here

Figure 4

Age of Survey Responders



Following is a summary of the questions asked on the questionnaire, with accompanying statistics.

1. Year you contracted polio (age contracted polio). One hundred three respondents did not answer this question, leaving a total of 599 respondents.

Group I, a total of 347, or 58 percent, contracted polio during the major epidemic years of 1946-1956. Prior to 1946 and subsequent to 1956, the Group II total was 181, or 30 percent. During the major epidemic period of 1946-1956, no responders contracted polio who were between the ages of 19-34 years or older than 54 years of age.

Table 4

Age Contracted Polio

Group I

Contracted Polio Between 1946-1956

| Age | Number | Percent of Total |
|---|---|---|
| 0-18 years | 195 | 56.1 |
| 19-34 years | 0 | 0 |
| 35-38 years | 7 | 2 |
| 38-54 years | 145 | 41.9 |

Table 5

Age Contracted Polio

Group II

Contracted Polio Before 1946 or After 1956

| Age | Number | Percent of Total |
|---|---|---|
| 0-18 years | 160 | 88.3 |
| 38-54 years | 21 | 11.7 |

2. Type or types: Cerebral, Bulbar, Spinal, Respiratory, Don't know.

Of the 700 total respondents, the type of polio contracted was as follows: 315 (45%) spinal, 171 (24%) bulbar, 96 (14%) respiratory, 12 (2%) cerebral; 106 (15%) didn't know.

3. Physical Involvement; Muscle Weakness, Para, Quad, Ambulatory, Wheelchair, Braces, Respiratory Aids.

This question was answered by 320 individuals. During the heavy epidemic years, 179 people, 56 percent, became quadriplegic.

Table 6

Number of Quadriplegics

1947-1956

| Year | Number | Percent |
|---|---|---|
| 1946 | 2 | 6.00 |
| 1947 | 3 | 0.09 |
| 1948 | 11 | 4.00 |
| 1949 | 15 | 4.00 |
| 1950 | 14 | 4.00 |
| 1951 | 14 | 4.00 |
| 1952 | 23 | 7.00 |
| 1954 | 19 | 5.00 |
| 1955 | 36 | 11.00 |
| 1956 | 10 | 3.00 |

4. Hospitalization: Yes, No, Length of Stay.

More than 98 percent of the respondents were hospitalized and they remained in the hospital an average of one week to 28 years.

5. Treatment: Kenny Hot Packs, Physical Therapy, Occupational Therapy, Psychological Help, Respiratory Therapy, Tank Respirator, Cuirass, Monaghan, Huxley, Emerson, Other, Don't know kind, Multi Lung, Thompson, Bantam, Eureka Blower, Rocking Bed.

Not part of this study. Data unavailable at this time.

6. Were you weaned from the respirator?

Yes, 191.

7. Did you receive either Salk or Sabin Vaccine AFTER contracting polio?

All replies were NO.

8. At what point did you feel you were rehabilitated? Year?

This question was answered in many ways. Many respondents held they were never rehabilitated. Others expressed that rehabilitation occurred when they "went back to school," "graduated," "returned home," or "got a job."

9. Did you return to the community?

685 of 700 respondents returned to the community.

10. Did you remain in an institution?

15 of 700 people remained in an institution.

11. Have you been hospitalized since?

With few exceptions, all respondents had been hospitalized in recent years with a wide variety of complaints. Reasons for hospitalization included birth of children, pneumonia or severe cold, fractured arm or leg due to accident or fall, reevaluation of breathing, surgery, or gastrointestinal problems.

12. Have there been any changes in your physical condition?

Some respondents checked all, some checked one, some, none (based on 227 conditions checked, 1947-1956).

Table 7

Types of Symptoms

Group I

Respondents Who Contracted Polio

1946-1956

| Symptom | Number | Percentage |
|---|---|---|
| Depression | 64 | 28 |
| Dizziness | 48 | 23 |
| Interrupted Sleep | 70 | 38 |
| Gastrointestinal Problems | 78 | 36 |
| Fatigue | 78 | 36 |
| Returned to Respiratory Aids | 50 | 22 |

Six months later, when calculations were based upon 700 respondents, most respondents checked at least one category, indicating noticeable change. (In most cases, more than one category was checked.)

One of the first symptoms noted by polio survivors was interrupted sleep. It was assumed, at first, to be connected with age and the number of years which had passed since the onset of polio. Subsequently, this seemed irrelevant. No matter what the age was when a person contracted polio, this problem existed.

Shortness of breath appeared to be the most common problem (600 respondents checked this category), followed by dizziness (537 out of 700).

Insert Table 8 about here

Table 8

Types of Symptoms

N=700

| Symptom | Number | Percentage |
|---|---|---|
| Shortness of Breath | 600 | 85 |
| Dizziness | 537 | 65 |
| Depression | 311 | 44 |
| Numbness | 240 | 34 |
| Weakness | 169 | 24 |
| Headaches | 126 | 18 |
| Brittle Bones | 97 | 14 |
| Anxiety | 72 | 13 |
| Personality Change | 49 | 7 |
| Interrupted Sleep | 97 | 14 |
| Fatigue | 93 | 14 |
| Fractures | 8 | 0.01 |
| Blackouts | 3 | 0.04 |
| G/I Problems | 80 | 10 |

Before the great epidemics of 1947 to 1956, very young children were struck by the disease poliomyelitis, no longer known as infantile paralysis (Landauer, 1958). However, in the early fifties, it was discovered that polio was beginning to attack young adults leaving them not only paralyzed from polio but untrained vocationally and professionally. The team approach, or total rehabilitation, which includes physical, psychological and vocational counseling, was practiced at the regional rehabilitation centers.

People who contracted polio as children, and young adults disabled during the fifties, were excellent candidates for further education. Encouraged by their vocational counselors, and supported by the Office of Vocational Rehabilitation (OVR) for tuition, books and transportation to and from school, many students disabled by polio were able to attend college. Polio survivors were considered fortunate because the virus was assumed to be over and further progression was not indicated. Two professions--speech therapist and vocational rehabilitation counselor--were especially adaptable for individuals who had polio.

Three hundred and ten respondents replied to the query on education.

In Table 9, it appears that more individuals were given the opportunity of higher education during the years 1947-1956 than in the previous period. Probably, much of the cedit is due to the financial support of the Office of Vocational Rehabilitation.

Table 9

Education

1910-1946 and 1947-1956

| Degree | 1910-1946 | | 1947-1956 | |
|---|---|---|---|---|
| | N | % | N | % |
| Masters | 31 | 11 | 70 | 16 |
| Bachelor's | 46 | 16 | 87 | 20 |
| Associate | 6 | 2 | 31 | 7 |
| Some college | 78 | 27 | 92 | 22 |
| High school | 72 | 25 | 98 | 22 |
| Less than High | 24 | 8 | 2 | .05 |
| Ph.D., M.D. | 13 | 4.5 | 19 | 5 |

## The Legacy

Twenty-five or thirty years ago, it was everyone's understanding that polio was "over" after the acute stage. This apparently is no longer true. Too many emergencies, too many physical and financial problems, awareness heightened by so many polio survivors in distress, all point out the contradiction.

The following excerpts were taken at random from the 700 questionnaires used in this study.

Some responses to question 22, "What future resources do you think should be developed for your well being?" were:

Case 1.

> A clear statement of what to expect so I can plan my last year(s).

Case 2.

> A cure for high blood pressure, overweight, dandruff and middle age. Other than that, the love of a good woman.

Case 3.

> Recognition as a viable group of people as opposed to leftovers from a dread disease. A newsletter about post-polios who made it.

Many people added information not specifically asked for and these excerpts reveal some of the social, physical, psychological and financial concerns of the respondents.

Case 4.

> I got in bad condition. They sent me to the University of Michigan - Division of Pulmonary Medicine in Ann Arbor, Michigan to see another doctor. After they dried me out (so I could lie on my back) they put me in the iron lung.
>
> This is another story, but I couldn't make myself get in and stay. So, they got a Monaghan respirator but that wouldn't do it. The doctor told me the only way I was going to live through this...I would have to sleep in the iron lung...so I did.
>
> They got me one for my home and they also put me on oxygen at 2 liters per minute 100% of the time. So, for about 2 years I slept in the iron lung. Then I got headaches again and they took me out of the lung and I started using the Monaghan and I use it every day and will keep using it until the last.
>
> Since leaving Michigan and living in California, I feel better and am more active.

Case 5.

I feel the March of Dimes should help provide therapy, personal health care needs, i.e. respiratory equipment, transporting equipment (wheelchairs, lifts) and some help in attendant care service to help keep us out of institutions and maximize our quality of independent living. I think the March of Dimes has abandoned the original intent of its founders by changing the focus to birth defects.

Case 6.

Doctors I have gone to do not know anything about polio so I don't go any more unless I know something is really wrong. Physical therapy would help.

Case 7.

I am an "odd ball". Am on a list of the 75 most seriously involved in this area, yet I alone on my ward learned to walk. I can get around on good days as far as my breathing will permit and look much stronger than I am. Besides my breathing, my weakest point is my neck, and I dislocate my spine many times a day, and more often in bed at night. This causes headaches, as well as back of the neck pain. Can't get up without a chair when I fall. Because of poor breathing, I find it harder and harder to get dressed, to eat properly, and never get the house clean, just here and there.

At present, I am taking painting lessons....I am told I am quite good but very slow. I would like to earn enough to pay for hired help to do heavy cleaning. I feel I should have been trained to support myself using my brain rather than "keeping house". I also could have used psychological help, still could, I suppose. I live out in the country, but, since the rattle-snake was on the front porch, I'm afraid to go out without someone else.

Case 8.

The more I think about Medicare the madder I get. I bought a $2,500 electric wheelchair. Medicare first denied any help, then allowed $750. Two friends bought the same equipment. One paid $1,500 and Medicare allowed $750; the other paid $2,300 and Medicare allowed $1,896. All were processed through the same office.

My other bitch concerns rental equipment. You may be aware that respo's eligible for Medicare have their equipment maintained by Lifecare Services rather than the March of Dimes. Lifecare says they "bought" my rocking bed and lifter from March of Dimes. I can just imagine what price was paid for my 25 year old equipment. Medicare had since paid enough rental for me to have purchased new equipment when they took over. In fact, it galled me so much that Lifecare got over $700 in rental fees for my old lift that I had my parents buy it outright from Lifecare for $150. You know what Medicare paid us for that? $120! I'm thinking about getting a loan to buy a new rocking bed ($2,350) if Medicare will pay us $78 a month the same as they pay Lifecare. Then again, I think, why bother?, it's no skin off my nose if Lifecare bleeds Medicare. Everybody else seems happy with the set-up. When I think about it, I feel used...even though Lifecare serves me well. For those fees, they certainly should. Now that's off my chest....

Case 9.

After my 1978 stay in the hospital, we had a very high bill...$8,000. Since I was unable to get any insurance, we were faced with a very large debt. I contacted the March of Dimes to see if they had some program to help me. I was told polio isn't any more and they only help birth defect children. Needless to say, we are still trying to pay our bill, but still owe over $2,000. Since my husband is in construction on the foreman level, jobs are few.

I was very shocked and sorry to think that the March of Dimes which was founded for the polio victims was no longer concerned about us.

Do you know why?

Case 10.

It has always seemed to me that bureaucratic guidelines for financial aid from the Government, such as SSI for disabled people is very unrealistic. Why does one have to be at poverty level before SSI will help with attendant care? Why will they pay over $1,000 a month to help people in nursing homes when some could survive outside if funds were available for attendant care? The average family cannot afford the financial strain to pay for the attendant but are quite willing to provide lodging and food. It seems to me that so much money is wasted on dumb government grants...like $25,000 for research to see if a monkey would be able to take care of a quad...great...who will take care of the monkey? There is just so much waste...

Both of my parents are dead. I live off a very small trust fund that in 2½ years will be wiped out. What then...I owe $41,000 on the mortgage. It costs me $2,000 a month to maintain myself. With some financial help I could last longer. Can't sell the house because of interest rates, wouldn't solve anything to sell it anyway. I realize these are hard times for a lot of people but a quad not strong enough to get out there and work, and the struggle to survive, zaps all their strength and they never get into fulfilling their potential.

Case 11.

When I came home from the hospital, I lived with my parents who took care of me for fifteen years. My father is 80 years old now and my mother is 78. Needless to say, they are no longer able to take care of me.

The past ten years of my life have been spent in a constant struggle to keep dependable help. I get $200 a month Social Security, and there is just no way that you can live and pay someone to take care of you for this amount of money. Because of lack of money I have been left many times with nobody to put me to bed at night or to get me up in the morning. I can't even begin to tell you how hard I have struggled with this problem through the years. The March of Dimes has been wonderful to help me with medical equipment but they refuse to give any other kind of financial assistance. People seem to think that just because we have a polio vaccine now, there is no polio. THIS IS NOT TRUE!!!

Case 12.

After living a normal life as a wife and mother of four, my condition began to deteriorate in 1968, with marked increase in shortness of breath, chest pain upon exertion and general weakness. The physicians who I consulted attributed my condition to angina and/or emotional problems and hypochondria. Then in 1980 I was in an auto accident in which I received a hard blow to the chest. Several days later I went into respiratory failure and was "trached". The pulmonary specialist then called in to treat me obtained an "iron lung" from Augusta and when I could be out except at night I was allowed to bring it home. I used it for seven months at night during which time my physician tried to wean me away completely but I never succeeded. He then switched me to the Monaghan. He still thinks I am psychologically attached to it because I am still using it at night for several hours. But I realize now that the sleep problems I was having before the accident, i.e. nightmares, headaches, needing three pillows, probably indicated the need for more aid then.

Case 13.

We just got your letter. We tried to fill it out the best we could. I am Juanita's mother. I am 75 years old. I wait on her but it worries me at my age if something happens to me. What and where she could go, I don't know. I have no one that could take care of her. She and I live alone.

She has to have help all the time with her breathing.

Case 14.

My condition demands the rocking bed AGAIN, 22 years post-onset. Badly involved hands, arms, pectorals, are principle handicap, but are assistive enough for driving automobile and light housekeeping. Not able to do sustained work for any time at all.

Would it not be "fair" to be able to claim an extra exemption on income for victims who cannot seek employment as a result of polio or any other dread disease?

Younger doctors do not even know what a rocking bed looks like. They now use expensive and uncomfortable equipment and even tracheostomy. Unless patient ORDERS rocking bed from Augusta, then lawyers from the hospital worry about it.

Case 15.

I believe lack of information not lack of concern may prevent proper medical care. My internist did not know of the findings reported at the first convention until I discussed what I had read with him. He then asked to borrow the material so he could read it for himself.

## Comments

These excerpts are based on the letters and comments that were attached to many of the questionnaires plus personal interviews with some individuals throughout the country.

Looking back, polio survivors remember how successfully the National Foundation for Infantile Paralysis, March of Dimes, convinced people, through their annual fund-raising events, that poliomyelitis was conquerable. It was simple...if individuals tried...if they had hope and faith, they could beat the devastation of the disease. It was a version of the All-American Dream, with the hero, Franklin Delano Roosevelt, beating the bad guy--polio--and emerging as victor holding the highest office in the country.

For individuals who contracted polio, became paralyzed, separated from family and friends, time was needed to adjust to a new life. As people recognized the results of poliomyelitis and acknowledged the disabilities with which they would have to live, they realized how difficult it would be to be different--disabled. They were angry at their bodies for not responding to treatment by physical and occupational therapists, bodies which were not getting back to normal. No one could answer the questions, why me? or, what did I do to deserve this?

An adjustment to the disability took on the same stages experienced in grieving over a loss. It could be said that there is a universality to adjustment to the disability rather than acceptance. The stages of adjustment are comparable to Dr. Kübler-Ross's "Five Stages of Dying." The five stages of adjustment do not have to be followed in any order and can be reversed or postponed (Kübler-Ross, 1969).

Anxiety, denial and anger can be repeated many times during the first months and years of acceptance. An illness like a cold could become a major setback. It could create stress, anxiety and fright if the individual needed to be placed in a tank respirator. Denial of the illness and the resulting disabilities, anger at the situation in which they found themselves, anger toward self and family, bargaining with God, with everyone...all apparently failed.

The great loss of independence, body function, breath, depression, associated with loss and grief, necessitated a mourning period before starting a new life. Acceptance of a disability occurs when "better" becomes the reality of a situation and the ability to cope with it physically, socially and emotionally. Not unlike people who live without physical disabilities, disabled people live every day as a challenge.

Polio survivors returning to the community generally considered themselves rehabilitated, and sought to be accepted like non-disabled in their communities. Many, in fact, became part of the community and lost their identity as a special group--the polio survivors. Many were determined to simply get on with their lives by going to school, back to jobs, if possible. They married and started families or returned to their families.

### Equipment

The havoc wrought by poliomyelitis was decreased and almost eradicated by the introduction of the Salk vaccine. The iron lungs were moved to the basements of hospitals where they remain today, unused, with few health professionals who remember how to operate them. The polio survivors who suddenly need tank respirators have a problem being treated.

One of the goals of rehabilitation is for people to return to their communities and live satisfactory and meaningful lives within the boundaries of their disabilities. When people who had polio were rehabilitated thirty years ago, they received the necessary equipment, such as respirators, special beds, lifters, and even money for attendant care, from the March of Dimes. Many people who had polio felt that this support would be continued, for was not their support the reason for the organization in the first place?

Perhaps because so many children were afflicted with poliomyelitis through the country, the Mothers' March Against Polio raised huge sums of money. The March of Dimes provided the best possible training for medical students, physicians, and other health professionals, and supported researchers. Poliomyelitis was the first disease in which life was prolonged after breathing had stopped. This led to the development of artificial ventilation, modern anesthesiology and heart-lung machines. Philip Drinker, Professor of Engineering at the Harvard School of Public Health in Boston, wanted to build a machine to help polio victims with respiratory failure. His brother, Cecil Drinker, Professor of Physiology at the Harvard School of Public Health, told him it would be of no use. He built it anyway and many lives were saved during the 1930s and 1940s. The Drinker iron lung saved people from dying and forced doctors to face the problems of caring appropriately for those who lived (Paul, 1971).

Philip Drinker didn't want the patent for the respirator, tried to give it to Harvard University and, finally, gave it to Warren Collins, the manufacturer.

Around 1932, Jack Emerson, son of Dr. Haven Emerson, past Commissioner of Health in New York City, designed the Emerson tank respirator, "iron lung." It became more popular than the Drinker because it was less expensive, easier to use since the bellows had been installed at the foot, and was very reliable.

Rocking beds began to be used during the late 1940s. The TOMAC, manufactured by the American Hospital Supply Company, was replaced by the Emerson beds because of smoother performance, lower cost, and simplicity of design.

The development of the chest respirator has been mainly from Colorado. The first portable chest respirator was designed by Monaghan in the late 1940s and, compared to today's machines, was cumbersome and bulky--but, it made life better for those using it. Huxley, Thompson, Multilung, each new development was a giant step forward for polio survivors. The companies merged or went out of business and, about fifteen years ago, Life Care Products was established by Jim V. Campbell as a natural spinoff from Thompson.

So, today, Emerson and Life Care Products are available; Thompson has just merged with Bennett.

The experimental work with a cuirass (breast plate) made people easier to handle and exposed them to room air. Not as effective as the iron lung which did 100 percent of breathing, the cuirass was 85 percent as effective. The rocking bed, developed by Jesse Wright of Philadelphia, in 1945, was most useful in the treatment of mild respiratory involvement. Positive pressure breathing was originally air pumped into the lungs through a tracheostomy tube. During the 1952 epidemic in Denmark, volunteers pumped bicycles to provide the necessary power to keep respirators running.

The country was mobilized to direct the quality of services necessary for people to reach their highest potential. Education often included home tutoring so children could be on grade level, or, if they remained in the hospital, special schools were created.

Housing adaptations were necessary in many instances, and money was provided for this, too. Transportation to and from the hospital was paid for. For individuals who had worked and needed to be retrained, vocational rehabilitation counselors were available to assist.

Once the long-sought after vaccine was realized, it became a victory for some--those who did not get polio. For those who had polio, it was the end of an era, leaving many in jeopardy of their lives, and certainly altering their quality of life. Many of the people who were stricken with polio before the great epidemics of 1947 to 1956 never received the benefits of the services of the March of Dimes and had to fend for themselves.

Add to this the anguish experienced by individuals who thought that once polio had run its course and done its damage, it was over.

The quality of life of polio survivors can be the same as anyone else's. Financial concerns loom the largest, particularly when there are constant threats of cut-backs to all services. There is a lack of uniformity in Medicaid from state to state. For individuals who are dependent upon pension benefits, the amount of money received is less than adequate. Cost of living adjustments have been made, but fail to meet actual increases in the cost of everyday living. Bureaucratic guidelines to financial aid from the government are unrealistic and imperil life. This is particularly true when attendant care, transportation to and from hospitals and physicians, and equipment to get in and out of bed or bath tub are needed.

For many polio survivors who have been cared for by family members, the strain now seems insurmountable. Parents have become thirty years older, are still willing but unable to provide daily care.

Now that the threat of polio has been removed, no one seems to care. There are no telethons for polio, and, except when celebrities such as Alan Alda, Dinah Shore and Itzak Pearlman, who had polio, are interviewed, the disease is never mentioned. Many people who had polio years ago are not hospitalized or do not see a doctor. Many physicians are unfamiliar with the problems and attribute complaints to psychological reasons.

Often, physicians do not include a respiratory evaluation as part of the examination. The results of the Post-Polio Questionnaire indicate that at least some of the problems--shortness of breath, interrupted sleep and dizziness-are related to respiratory involvement.

The memories have faded about the yearly polio epidemics and the huge numbers of children afflicted each year. When the effectiveness of the Salk vaccine was measured, polio virtually wiped out, the problems of how to treat people who had polio were left unanswered.

Although the polio vaccine continues to be effective, and very few cases are reported each year, the "residual" paralysis to which individuals adjusted 25 to 30 years ago may not be the end. It was reported that muscle weakness, pain and headaches were surprising symptoms of a health problem with a "broad and mysterious" scope. Similar symptoms were described by people with varying degrees of physical involvement. Pain and muscle weakness were often felt in the unaffected side of the body, the side not involved with the disease 25 to 30 years before.

Dr. Ann Bailey, Roosevelt Institute for Rehabilitation, Warm Springs, Georgia, sums up the old opinion about polio: "You had it, you had a period of time to regain some or all muscle control, and that was the end of it." In recent years, scattered reports from people who had polio challenge this long-held opinion, claims Bailey.

Something is happening to the estimated 300,000 polio survivors. This questionnaire substantiates the physical changes that seemed to be happening. The most startling figure was that 600 of 700 polio survivors reported experiencing interrupted sleep. The comments written by the respondents, and selected from the 700 questionnaires, revealed there is an apparent underlying feeling of panic, and hostility.

Panic manifests itself by not having physicians who understand the problems individuals who had polio 25 to 30 years ago are now experiencing. Further, until the last three years, neither the individuals who had polio or their physicians, connected the present physical difficulties with polio. People who suffered from extreme fatigue, dizziness, shortness of breath, interrupted sleep (refer to Table 8) were often referred for psychological or psychiatric treatment. Physicians who had never treated people who had polio were being asked to diagnose and treat the problem. Symptoms such as extreme fatigue, depression, dizziness, shortness of breath were difficult to evaluate. Physicians also had few resources they could contact.

Some people are experiencing great physical difficulties, while others appear to have no present problems. There appears to be a wide variance among the individuals experiencing difficulties, with no pattern in age, treatment, or physical involvement.

Hostility has centered around the inability to find help as well as validating that problems are occurring. As the National Foundation, March of Dimes has changed its focus, individuals who had polio have been left without a voluntary service organization. Polio is one of the few disease categories without a central resource.

Aging parents are no longer able to care for their now-grown children. Financial benefits vary from state to state and people report an inability to keep abreast of the rules of agencies. The physical problems, the lack of physicians with expertise and resources, and the validation of the problems, has added tension to an already difficult situation.

The Polio Information Center was established with an extremely ambitious program which included the following:

1. Establish a referral service for medical, social and psychological services.
2. Encourage research for all rehabilitation services.
3. Publish and disseminate polio related materials for consumers and professionals.
4. Publish guidelines for rehabilitation evaluations, including, but not limited to, respiratory function, occupational therapy, physical therapy and vocational rehabilitation counseling.

5. Make available relevant rehabilitation engineering research.

6. Support research of drugs being prescribed.

7. Instigate a study of the relationship between weaning from the respirator and current respiratory dysfunction.

8. Analyze, evaluate and publish the findings of the Post-Polio questionnaire.

9. Open a hot line.

10. Maintain a permanent file of polio survivors.

Interest has been expressed in the findings of this questionnaire. It is the most recent, comprehensive study of polio survivors. Two other studies, from Warm Springs, Georgia (by Ann Bailey, M.D.) and Manitoba (Joe Kaufert) are researching post-polio syndrome within their institution or geographic population. This post-polio study represents polio survivors from all but a few states, all age categories, education, and validation of the crisis.

## First Post-Polio Conference

A three-day symposium, "The First International Conference on Respiratory Rehabilitation and Post-Polio Aging Problems: What Ever Happened to the Polio Patient?" was held in Chicago, Illinois in October, 1981. Co-sponsored by the Rehabilitation Gazette and the Rehabilitation Institute of Chicago, it was the first conference since the late 1950s to be concerned with polio. The people who participated were experts from the medical community, doctors, nurses, occupational, physical and respiratory therapists, equipment manufacturers and people who make repairs, plus many individuals who had first-hand experience by having had polio.

The conference was unique; physicians were learning from individuals who had polio--individuals who knew their bodies, their problems, equipment and life style. The probability was that they had more experience than anyone else.

There was a great deal of controversy at the Conference. Among the physicians who delivered papers, there was enormous diversity of opinion, ranging from statements by one participating physician that there was no particular post-polio syndrome, to another who referred to it as part of the aging process that everyone experiences, but which was exacerbated in people who had polio. One physician believed that proper diet and balanced energy output would contribute to quality of life. A respiratory specialist maintained that the results of her work, spanning twenty-five years, seemed to indicate that a proper physical evaluation including respiratory functions, occupational and physical therapy evaluations and psychological interview would be essential. Another physician who was from England came with still another premise. Primarily, his contribution was to enlighten everyone regarding equipment, care and treatment in his country.

This wide range of inconclusive information caused painful frustration and heightened anxiety among the participants. The Conference, however, served as a forum to address and, indeed, validate that people who had polio, no matter the age of onset, the type of polio or the area of the country in which they lived, were having unexplained physical problems and pain.

Harriet Bell presented some findings of the Post-Polio questionnaire at this conference, and also described the establishment of the Polio Information Center.

The direction that the conference took, no matter how divided the opinion of participants, was that something must be done to address the needs of polio survivors.

Disabled USA, speaking of the present situation of people who had polio, referred to the March of Dimes campaigns to raise money.

> These people are, however, no longer endearing and vulnerable children for whom a nation pours out millions in dollars and volunteer hours to save and protect. They are adults now. They want to enjoy the fruits of their life work and have peace and tranquility in their old age. To do so, they may need, once again, specialized health services, commitment from others, and perhaps another advance in the state of medical knowledge. (Disabled USA, 1982)

Although there was controversy, there was consensus of the following (Achievement, 1982):

1. Polio is a disease that still is in existence, therefore education and research in the area are still necessary.

3. It has been estimated that from eight to ten million children have not been vaccinated against the disease. Mandatory vaccination requirements are either not uniform throughout the U.S. or are simply not strictly enforced by the schools.

3. Polio occurrences are reported to the Center for Disease Control in Atlanta, but are not publicized locally. Incidences are not of epidemic proportions in the United States, but there <u>are</u> scattered cases of polio.

4. A major concern should be consciousness raising of both health care providers and recipients.

5. An interesting and alarming point was raised concerning the potential of contracting polio. Certain areas such as Central and South America, where polio remains endemic, require no polio immunizations to travel there. Yet, the World Health Organization has reported polio to be rampant in Third World countries.

At the First Post-Polio Conference, Eugene Murphy Ph.D., Veterans Administration, New York, a bio-electric engineer who had polio, emphasized the need for collecting and disseminating reliable information to the medical world and disabled individuals. He stressed the fact that long-term results affect the treatment of the individual and can be used in the rehabilitation of others, i.e. the critical care nursing which influenced the treatment of spinal cord injured in the seventies.

"Society tends to equate ability with maneuverability and physical ability," stated Marilyn Saviola, Vocational

Rehabilitation Counselor, New York, disabled by polio. "If one is less physically able, does one become less human?"

The Vice President and General Counsel of the March of Dimes, John O'Connor, was confronted by people with strong feelings of resentment when he stated that the organization serves the respiratory needs of about 700 polio survivors across the country. Many participants felt the March of Dimes should once again become actively involved not just with respiratory equipment but with the total health careneeds of all polio survivors. The abandonment of polio survivors who do not have a foundation to assist them was met with outrage.

A positive aspect of the Conference was a growing interest in the problems.

The Conference was informational and much work was done trying to identify the extent of the problem and attempting to provide potential solutions. The potent force of the Conference came from participants, validating that they were not alone in their awareness of the problems.

It has been noted that for the most part, many physicians, unaware and unfamiliar with the long-term effects of polio, do not consider the possibility that these symptoms are polio related. This can, and does, lead to inappropriate treatment. Research, information, education and exposure of health care providers to this information is necessary, in order to devise some solutions for more appropriate care. It is important to stress that the person with post polio requires medical attention that is highly individualized, and they themselves most often are the most valuable resource with regard to factors concerning changes in his or her usual physical status. It is therefore imperative that active participation and collaboration continue between health care providers and recipients.

This Conference also brought to light the need for a stronger communication network between providers and consumers of health care services, as well as among the consumers and among the professionals themselves.

All health professionals should have training and a central resource hotline for information regarding post polio. Research into ventilatory and orthotic aids and technological advances such as energy saving devices and research into rehabilitation engineering should be fully utilized.

There was an opportunity for researchers and physicians to discuss their work on pain, weakness and fatigue and to share their thoughts on causes and strategies for coping.

The polio survivors also had the opportunity to question the medical professionals and present their own health problems.

For most of the issues raised, little in the way of immediate relief exists (Disabled U.S.A., 1982). In spite of the fact that polio survivors have outlived the manufacturers of breathing equipment--Drinker, Emerson and Monoghan--the technology to provide relatively portable and effective breathing equipment already exists. They have also outlived the medical professionals who knew anything about the usefulness of different types of respirators. "One reason for the availability of this equipment is due to the coordinating effort and financial subsidies offered by the March of Dimes," stated John O'Connor, Vice President. "The March of Dimes budgets over $600,000 a year for respiratory equipment and its maintenance for 700 polio survivors across the country."

The involvement of the March of Dimes during the great epidemics created an historic cooperation among the different disciplines treating polio and it fired the work of researchers investigating the polio virus and those who developed the vaccine. Some conference participants said that there is a need for a new, comprehensive effort to investigate the problem. The need for research was repeated by all who are familiar with the post-polio syndrome.

Augusta Alba, M.D., stated that although the number of survivors, 250,000, is relatively small, the research could be applied later to other individuals needing specialized rehabilitation.

Perhaps the underlying force of the Conference was the coming together of polio survivors from different parts of the world. Each had a different degree of disability as a result of polio, many years before, and each had a concern about new physical difficulties.

# Chapter III

## Questionnaire II - Post-Polio Women and Marriage

In an effort to further determine the quality of life of polio survivors, a second questionnaire was developed by the author. Distributed during 1983, it was directed to women disabled by polio and sought to evaluate whether or not disability before or after marriage affected the length of time or stability of the marriage.

The total study, two questionnaires, began with the Post-Polio Questionnaire discussed in Chapter II. The replies and comments led to a search for more information about the quality of life polio survivors are experiencing. The second questionnaire was developed to study conflicts experienced by disabled women in marriage. Entitled "Women Disabled by Polio and Marriage," it supplies interesting social data. For comparison, a group of twenty-five non-disabled women was included in this study.

The complete study, two questionnaires, was based upon the names of the first seven hundred (700) respondents to the Post-Polio Questionnaire. Four hundred and sixty-four (65%) are women. The questionnaire was mailed to 400 women (57.6%) across the United States. There were 246 respondents (N=246) representing 61% of the total.

The average age was 52.6 years, 62% of the total. One hundred and twenty-one letters were returned, addressee unknown.

One hundred and seventy-six women (71%) live in urban areas in this country; 43 (17%) reside in rural areas and 27 (12%) did not reply to this question. Ethnicity was as follows: 1 American Indian (4% of the total); 0 Asians; 2 Blacks, 8% of the total; 1 Hispanic, 4%; and 219 Whites (88% of the total). Nine women (2.3%) did not answer the question.

Seventeen percent, 46, of the disabled women are married to men who are also disabled; 97 (39%) are married to non-disabled men, leaving 106 women (44%) who did not reply to this question.

The responses in Questionnaire I, the Post-Polio Questionnaire, indicated that polio survivors are quite well-educated. This appears to be validated in Questionnaire II: only 11 women (4%) attended less than high school; 115 (46%) attended high school; 51 women (20%) hold Bachelor's degrees; 31 (12%) have Master's degrees; and 4 (1%) have a Ph.D. Fifteen (5%) are in a separate category, high school plus, which includes nursing, business school and any study after high school. This leaves 19 (7%) who did not answer this question.

When the questionnaire was distributed, both the age when polio was contracted and the present age were requested. The ages at the time polio was contracted range from 2 to 34, with 14 under age 18, indicating marriage after disability. The age spread compares with that in the Post-Polio Questionnaire and shows clearly the length of time between onset and present. Twenty women (8%) did not reply to this question.

Table 10

Women

Age, Onset, Present

| | Onset | | Present | |
|---|---|---|---|---|
| Age by Year | Number | Percent | Number | Percent |
| 1-10 | 88 | 35 | - | - |
| 10-20 | 61 | 27 | - | - |
| 20-30 | 37 | 14 | 5 | 2 |
| 30-40 | 18 | 8 | 37 | 14 |
| 40-50 | - | - | 62 | 23 |
| 50-60 | - | - | 74 | 31 |
| 60+ | - | - | 48 | 19 |

Women who were separated, 3, had lived with their husbands 2, 18, and 20 years before being separated. They were separated from their husbands for 9, 18, and 14 years, respectively.

Divorced women had an average age of 57, were an average of 16 years of age when they contracted polio, lived with their husbands for an average of 12.5 years and were divorced an average of 11.5 years, with a span from 2-23 years married and 2-28 years divorced. Seven major reasons for divorce were isolated, but the numbers reflect just a part of the reason.

1. Disability: 13 women (5%) stated that their disability, plus additional expense (money), plus incompatibility due to additional expenses (money), led to alcohol abuse which was also caused by too much responsibility.

2. Money: 14 women (6%) listed money as a reason for divorce. The comments on the questionnaire tied together money, incompatibility, alcohol abuse and too much responsibility.

3. Incompatibility: 21 women (9%). Almost all of the respondents claimed incompatibility as a reason for divorce.

Again, the categories overlap--disability, money, incompatibility, alcohol abuse and too much responsibility.

4. Alcohol abuse: 12 women (5%) reported alcohol abuse as a cause, but, again, only in conjunction with the other factors.

5. Child abuse: 2 respondents (1%) reported child abuse as the reason for divorce.

6. Lack of privacy: 4 women (2%) claimed lack of privacy as a major reason for divorce.

7. Too much responsibility: 11 women (5%) stated that too much responsibility, added to disability, money, incompatibility, and alcohol abuse, was a major reason.

The total number of women who are not married is 78 (32%); women who are married, 120 (48%); women who are separated, 3 (1%); women who are divorced, 24 (9%); women who are widows, 21 (9%).

Family income ranges from very low, $10,000 or below for 49 (20%) of the women, to $40,000 or more for 29 (11%). Sixty-five families (26%) had an income of $10,000 to $20,000; 47 (20%) were in the $20,000 to $30,000 category, with the remaining 22 families (9%) earning $30,000 to $40,000.

One hundred and thirty (52%) of the women work; 94 (36%) do not; 22 (9%) did not answer this question. Seventy-five women (30%) work at home doing housework, cooking, tutoring, painting and volunteer work; 107 (48%) work away from the home in a variety of positions--office work, self-employed, teaching, health professionals or administration. The majority (28%) work in offices.

Twenty (8%) of non-disabled women work out of the home as teachers, health professionals, home care attendants, and telephone workers and their husbands are business executives, teachers, computer operators and drivers. These facts appear to agree with those compiled for disabled women, including the type of position held by either husband or wife.

Forty-nine men (19%) husband or significant other, work in the home; 11 (5%) do not. There was no answer from 186 (75%) of the men. Forty men (15%) work at home professionaly; 62 (25%) work outside as administrators, bankers, laborers, professors and in offices, the majority (12%) being professionals.

Although the majority of families have no help except from each other, 43 (17%) have housekeepers; 22 (8%) have home attendants, and 3 (1%) have baby sitters.

Family activities were divided into three general groups, civic, religious and recreational. 158 women (64%) participated in civic activities; 75 (30%) did not; 13 (5%) did not answer the question. 61 husbands (24%) participated in some civic activities; 45 (18%) did not; and 6 (6%) did not answer this question. 51 children (21%) take part in civic activities; 35 (14%) do not; 16 (6%) did not answer this question.

Religious services are attended by 143 (58%) of the respondents; 79 (32%) do not attend; and 64 (26%) did not reply. Husbands attend less often; 68 (28%) said they attend; 43 (17%) do not attend; and 25 (10%) did not reply. Children appear to attend church activities even less, with 65 (26%) attending; 31 (13%) not attending; and 34 (14%) not answering this question.

Recreational activities seem to be fairly well attended, with 119 (48%) of the women participating; 60 (24%) did not answering this question. Husbands appear to attend fewer activities, with 79 (32%) participating; 57 (23%) did not reply. 88 (11%) of the children participated, with 77 (31%) not replying.

Family relationships were divided into six categories beginning with relationship with husband. 113 (45%)

respondents did not answer; 75 (31%) of the women have excellent relationships with their husbands; 26 (16%) rated their relationship as "good"; 10 (5%) rated it as "fair"; and 1 each (4%) rated it "poor" and "bad".

Evaluated on a five point scale, 134 (54%) of the women did not answer the question regarding sexuality. Forty-one (16%) rated their sexual relationships as excellent; 37, (15%) rated it as "good"; 11 (4%) rated it "fair"; and 10 (4%) rated it "poor".

Regarding relationships with children, 124 (54%) did not reply. Seventy-three (29%) stated excellent; 42 (13%) stated good; 5 (2%) said fair; and 2 (1%) said poor.

In many instances, the category of grandchildren did not apply because the respondents were too young or not married. In fact, 189 (76%) did not answer the question, but 41 (16%) rated the relationship excellent; 14 (6%) rated it good; and 2 (9%) rated it fair.

The question of relationships with parents was not answered by 98 (39%) of the women. Of those who responded, 94 (33%) stated excellent; 43 (16%) said good; 6 (3%) said fair; 3 (1%) poor; and 2 (1%) bad.

The relationships with other relatives, although not specified, were 99 (42%) excellent, 92 (37%) good, 15 (5%)

fair, 3 (1%) poor, and 1 (1%) bad. 30 women (12%) did not reply.

The second group of 25 women completed the same questionnaire in July, 1983 and the following information was compiled.

Table 11
Comparison of General Information

| | Women Disabled by Polio<br>Percent | Non-Disabled Women<br>Percent |
|---|---|---|
| Residence | | |
| Urban | 71 | 100 |
| Rural | 17 | - |
| Ethnicity | | |
| White | 88 | 40 |
| Black | 8 | 44 |
| Hispanic | 4 | 16 |
| American Indian | 4 | - |
| Education | | |
| Less than high school | 4 | 12 |
| High school | 46 | 44 |
| Bachelor's degree | 20 | 28 |
| Master's degree | 12 | 6 |
| Ph.D. | 1 | 4 |
| Income | | |
| 10,000-less | 20 | 0 |
| 10-20,000 | 26 | 28 |
| 20-30,000 | 20 | 40 |
| 30-40,000 | 9 | 12 |
| 40,000+ | 11 | 20 |
| Work | | |
| Total | 52 | 100 |
| Women, out of home | 48 | 8 |
| Women, at home | 30 | 2 |

## Legacy, II

It is only when personal experiences are shared that statistics come alive. The following comments from the questionnaire illustrate this.

### Case 1.

> We have moved ten times since I had polio. Some places we have been active, politically and in church activities, some places not. For instance, in Oklahoma, I was county vice-chairman for the Republican Party and quite active politically. At present, I only vote. In terms of our activities, ...in Texas most of our activities were church oriented yet now we do not attend church regularly. Our faith is still strong. In fact, our older son, age 33, has gone back to graduate school, preparatory to going to India as a missionary. Four years in a little Eskimo village in the Alsakan bush where I worked as a radio operator for an airline in Alsaka, my only work experience since polio. Our lives have been full.

### Case 2.

> Husband couldn't cope with responsibility of home, up-keep, etc. At present, he's living with a young, able-bodied girl. I'm finding this divorce difficult to take as we were very happy for a number of years. He seems, in fact, to be going through the mid-life crisis syndrome.

Case 3.

My ex-husband could not handle my disability, even though I was handicapped when we were married. He finally admitted as much to me. I find other women with polio, married to non-disabled men who are physically attractive, who have been married long periods of time, now getting a divorce, either his choice or hers, but in all cases the men are womanizers. Interesting?

Case 4.

He was a polio from age 3; I married him at age 19 and I got polio at age 21½, three years later. Cause for divorce after 21 years...egotistic husband, jealous of my talents in business. He divorced me. God bless you. I am a Christian and admire you for this effort. I find few doctors who know about polio...mine just retired at 63. I am 30% recovered, 32 years in a wheelchair. Polio has made me fight harder for my place but I can claim many good and productive years in spite of it.

Being married to a polio was an experience. He was easily depressed and I was strong in my faith. Consequently, I was able to sustain my attitude on the positive side. Also, to help him the 25 years we were married and associated. Currently, he is in failing health and I am holding my own. I am single and he is married to a non-polio.

Case 5.

I think the toughest thing is not being able to find help to care for me, too much money. Not being able to remain independent (with the help of nursing assistance)...the frightful expense of illness...terrible burden for the family...t'ain't easy. I live alone and when help does not exist, my friends, my daughter become involved and I HATE it. So did my husbands.

Two husbands...both, alcohol abuse.

Case 6.

Spent too much time together due to costly transportation to go out and too much dependency on me to totally run our home.

Case 7.

I was married at 20 and polio at 23. At the time we had a 17-month-old child and I was pregnant. We were too young to handle our problems. He tried very hard, me too, but when our children were teenagers, the problems added up. Booze was the last straw. Remarried after six years and we are all very happy.

Case 8.

We separated before polio. He thought my parents had money. I didn't like being hit. He was a drinker and a gambler and that's why we had money problems. He never physically abused the children because he never saw them again after he left. He didn't want any responsibility but wanted everything else that went with marriage.

Case 9.

Even though my husband and I are separated, we are deeply committed to each other, have a good relationship, and desire to be together. Due to our disabilities, and low income, we are unable to maintain our home and hire the help we need. We are both severely disabled.

Case 10.

My divorce had nothing to do with the fact that I had polio, as my ex-husband married twice after our divorce and both marriages ended in divorce. He was more disabled mentally than I am physically. My physical disability is not that great. I find I am in better health than most of the so-called health nuts and physical fitness people I work with. I can accomplish more in a day than most people can in a week. I feel that my disability (what there is) is secondary in my life. Everything and everyone else is first.

<u>Case 11.</u>

My Dad is 69 years old and my Mom is 71. I help them with the housework and keeping up with the everyday chores. My 14-year-old daughter helps too. I had polio in September 1953 and my health hasn't been too good these past 12 years since I have been divorced. The polio affected my stomach muscles and since the Fall of 1982 and 1983, I have had gall bladder problems. During these 12 years I have gained 80 pounds and it is so hard losing it because of wearing a full length brace on my left leg and I cannot get around.

<u>Case 12.</u>

I contracted polio in 1925 in Paris, France. I spent a month there in the hospital and about 2 months in bed at home, in New York. Finished school first; went to Warm Springs, Ga. in 1929. Have returned there many times for advice. Elsewhere, doctors are not knowledgeable about polio. In recent years, have had to rely on those trained in prosthetics for help and advice.

<u>Case 13.</u>

My legs hurt me. I see that, being on them more at holiday times due to our business. I start having leg cramps, especially after I lie down. On weekends, I stay in bed all day Sunday to get more rest. One cannot cook, shop for children, clean house...without being on my feet.

Participation in outside activities for my children demands mother's help. I can't do it; I feel my children think I'm lazy. I want to cook good wholesome meals but can't due to my legs.

I have hip and low back problems. At times, I look like an old lady hobbling around.

My husband and one child are gaining weight. I'm sure it is because we eat out so much...it bothers me knowing if I could cook at home I would have a little more control over their meals.

I see myself as a grouch. When I stop, I can see I'm putting the demand on someone else, because I can't do it. I'll ask my husband or child to help. I'm unable to let them know how I feel. If I do, I'm a complainer. How can I let them know how I feel in a nice way that, due to physical handicap, I must limit my activities?

Case 14.

My desire for a career, finally growing up, discovering who I was and coming to believe I was competent and could be independent and coming to realize I married out of fear of not being asked again. My disability affected my marriage, I think, to the effect that I married someone I didn't love because of my own fears of being alone because I was disabled.

My husband used my disability against me in a custody struggle.

Case 15.

My husband died rather instantly of a myocardial infarct. He had no history of heart disease. Our marriage was good while it lasted.

Case 16.

I was doing very good but now have multiple sclerosis.

Case 17.

When I read about others who have had polio being cut off or out of touch, I believe my own life has been grace filled. In the area of relationships, nearly all my family relationships are in good order. My husband's recovery from alcoholism has taken place since 1975; in the past twelve months we have realistically entered separation which has led, finally in the past six weeks, to divorce proceedings in a very peaceful manner. Throughout my thirty-one years, I have only two negative spaces in adjusting; my medical, familial, relational, social, psychological, spiritual and intellectual support has been good and, at times, excellent.

Case 18.

I was working a full time job until my disability started to become worse. At first, I just cut my outside work down to part-time. About a year ago, I quit work outside the home entirely. I am still able to do all my own housework with the help of my one child. For now, my disability seems to be stable again.

Case 19.

I am in a wheelchair, very obese...feel isolated...low income...afraid of being broke...transportation too costly for recreation...I am vice president of Open Doors for the Handicapped, Pittsburgh Chapter. I do get out some.

Case 20.

The divorce questions happened five years after I had polio. My present husband is a para and we have been married 24 years and very happy. We raised 3 children. We have both had health problems and have to rest more now so had to give up some of our activities. My husband has provided very well for us.

Case 21.

I hope this doesn't sound too "pat" and too good to be true, but, I am extremely blessed to have a wonderful husband and three grown children. We all get along very well. I am physically able to participate in our church and civic and volunteer organizations.

I wear two braces and use crutches. I have an Amigo which I use at home; sometimes use a portable wheelchair away from home. Thanks to the Lord who taught me to live with my handicap, I have led a happy life. I raised three children.

Case 22.

My life is basically rich, diversified and satisfying, considering the restrictions of severe disability. My life lacked self-esteem and has been unself-disciplined since before I met him. I believe this, plus nearly 30 years of round-the-clock, year-round responsibility for me, has taken its toll. He is a deeply-disturbed man who can't, at present, get his act together...both to his frustration and mine. The lack of a job further restricts both of us causing additional frustration.

As to sex, he never seemed to want it much when I was able-bodied. We gave up all but kissing, hand-holding ten years ago.

<u>Case 23.</u>

> All polios...mentally alert...are like any able-bodied people. They live, play, work, and age with the same processes. They are independent as hell and find some way around their problem to be part of the community. Most are smarter than average.

The cases reported here were taken directly from the questionnaires. They represent the deep personal feelings of the respondents.

This questionnaire was completed by 246 disabled women and 25 non-disabled women, with, it appears, similar problems. Their questionnaires, selected for study, offered a wide range across the United States. The women, and their husbands, represented in this study, are mostly from cities, mostly white, upper middle income families. No signs appear to indicate which family has a disabled individual as part of it. They all participate in civic activities and some are regular participants at religious activities; women are more involved than either men or children.

Families experiencing divorce have similar difficulties. All of these families appear to have been assimilated into the community...there are no outstanding differences.

One questionnaire was inadvertently sent to a man who had polio. He returned the questionnaire unanswered, but with the suggestion that an additional survey be done on men. Another respondent suggested that an additional study be made of the children of polio survivors.

When this study began, it seemed probable that the woman's disability would present additional, insurmountable problems. Of the women who answered there was an acknowledgement of their disability, and yet the ability to cope was reflected.

## Second International Post-Polio Conference

The Second International Post-Polio Conference was held in May, 1983, in St. Louis, Missouri, in conjunction with a symposium on Living Independently with Severe Disability. More than 400 people, including many of the most severely disabled among polio survivors, met. After three full days of meetings, the participants concluded that polio is still endemic and epidemic in many parts of the world. There was agreement that insufficient research is being done regarding unanswered questions about the long-term effects of polio on polio survivors. What little knowledge there is on current health problems is not sufficiently relayed to physicians and other health professionals.

Polio may have been forgotten by most people, but not by the 300,000 American polio survivors who were paralyzed in the polio epidemics that struck during the 1940s and 1950s. Some were participants at this conference.

Little had been heard from these polio survivors. When the Salk vaccine became available in 1955-56, it virtually wiped out polio. Nothing more was heard from this group of 300,000 people who had polio. All the concern that had helped raise billions of dollars for the March of Dimes vanished. In 1960, the March of Dimes dropped polio and focused its attention on arthritis and birth defects.

Many conference participants sharply criticized the March of Dimes for abandoning polio survivors for the more lucrative crusade against birth defects. Some participants, who still receive services and equipment, defended the March of Dimes, acknowledging the accomplishments of the March of Dimes during the epidemics.

The First International Conference on Post-Polio was informational; the Second International Conference on Post-Polio was confrontational.

Agreement centered on the fact that some people who had polio are experiencing muscle weakness, shortness of breath and pain, after many years of stabilization. The controversy stands over the implications of the health problems being noted. The aging process, it was stated, is more apt to attack muscles already damaged severely, that the polio virus has no long-term effect, and, that treatment, such as using a respirator, and changing life-style, can return some individuals to better health. The one vocal minority contends that polio survivors are simply feeling the normal effects of aging and, there is no post-polio syndrome.

A second minority held an opposite view. They believe there is evidence of increased health problems which do not respond to standard treatments. While some individuals enjoy improving health, others are experiencing deteriorating breathing, endurance, and strength (*Disabled U.S.A.*, 1983).

Although medical research has been encouraged, but not financially supported, since the First International Conference on Post-Polio, little new was reported. Again, there were two camps. One connects today's physical problems with the polio virus contracted thirty years ago. The other, which explains present health problems with normal aging, claims they are treatable with present medical resources.

At the end of the conference, the question remained: "Is there a post-polio syndrome...or not?"

## Conclusion

Discussed at the Second International Post-Polio Conference was that polio is endemic and epidemic in many areas of the world, with an estimated five million new cases registered each year. The present immunization programs are not being implemented with sufficient vigor. According to a Lederle Pharmaceutical advertisement, six to eight million children in the United States have not been immunized against poliomyelitis. A major outbreak of the disease could once again cripple thousands of American children.

The many questions relating to long-term effects upon polio survivors are still unanswered. It appears that insufficient research is being conducted. The questions from Conference I are still unanswered, and further questions regarding physical changes polio survivors are now experiencing seem not yet to have been addressed.

Several speakers are doing research, but no data have been presented as yet. Dr. Marinos Dalakas, National Institute of Health, Rehabilitation Research, and Dr. Lauro Halstead, Texas Institute for Rehabilitation Research, have begun research programs. Some time during 1984, a medical symposium is being planned.

The available knowledge on the current health problems of polio survivors does not seem to have sufficient dissemination among health professionals. A particularly critical group of physicians are needed to treat polio survivors.

## Polio Information Center

By the time the Second International Post-Polio Conference took place (May, 1983), many people who had polio as well as physicians in fields related to polio knew about the Polio Information Center, as a result of the preceding conference, the questionnaire and a few articles published about its work. These included Human Services, a publication primarily geared to health professionals; Disabled U.S.A., which is the publication of the President's Committee on the Employment of the Handicapped; as well as Catholic News, Westchester Disability News and the Congress of Physically Handicapped Newsletter.

The Polio Information Center began unofficially the day the Post-Polio Questionnaire was published in the annual edition of the Rehabilitation Gazette (March, 1981). The names of Harriet Bell and Florence Weiner appeared on the Post-Polio Questionnaire.

People from across the country insisted that the work continue, not just for their own personal benefit and the physical and financial straits in which they found themselves, but for everyone. The questionnaire was completed by mother, husband, brother or sister of many people who had died of polio-related problems. They offered additional information and cooperation--to see the hospital records or autopsy report of their loved ones--if that could ultimately be of help to others. The Polio Information Center has functioned as follows:

1. Distributed the Post-Polio Questionnaire as part of the Rehabilitation Gazette (Spring, 1980). There was a small response due to the fact that many readers had muscle degenerative diseases, or were spinal cord injured.

2. Mailed the Post-Polio Questionnaire to rehabilitation institutions and hospitals with rehabilitation departments throughout the United States. Many institutions responded by saying that they respected the confidentiality of their clients and they could not disclose the names of either present or former patients at their institutions. In addition, the mailing lists were long out of date--people had moved, and, in some cases, had died. Their files were not categorized by disability, and they had no way of pulling files of individuals who had survived polio. Nevertheless, in a spirit of willingness to support the work, they referred the correspondence to the National Foundation, March of Dimes or Easter Seals.

3. Published the Post-Polio Questionnaire in the <u>Congress of Physically Handicapped Bulletin</u>.

4. Announcements were published in <u>Human Services</u>, <u>Accent</u>, <u>Disabled U.S.A.</u>, and <u>Achievement.</u>

5. Distributed the Post-Polio Questionnaire at several conferences.

Word of mouth, more than any other single source, became the major factor in the continuing growth of the Polio Information Center. Editors of disability newsletters, the Ontario March of Dimes and Centers for Independent Living have all expressed interest.

The 1984-85 objectives of the Polio Information Center include:

1. Complete the analysis of the Post-Polio Questionnaire and publish the results; make it available to the public.

2. Establish and maintain a permanent record of polio survivors.

3. Create a list of physicians and health related specialists for referrals.

4. Complete the establishment of the model Polio Information Center.

5. Raise funds for continuing work in this field.

6. Use this as a model for other regional centers throughout the United States and worldwide.

7. Establish the Polio Information Center as a not-for-profit organization.

The recurring plea of those attending the First International Symposium on Post-Polio was for the following:

1. A resource center where information could be disseminated.

2. A list of the names of physicians and health providers in all parts of the United States who are interesed in polio.

3. Training of physicians and allied health professionals about the needs of polio survivors.

By the time the Second International Conference was held (May 5-8, 1983), the Polio Information Center had published and distributed its first newsletter (Appendix C). This newsletter, which gave further credence to the existence of a Polio Information Center, was warmly received. Several researchers asked if the Center would join them in their work, specifically, Dr. Dalakas and Dr. Halstead, who described a two-fold plan of research in physical symptoms of individuals with post-polio problems and, a medical symposium directed to these concerns. From Manitoba, Canada, Joseph Kaufert, Ph.D., from Buffalo, from Texas, Indiana, and California, people turned to the Center for referrals and resources. Among those were individuals interested in establishing self-help groups, who asked that the Center serve as a conduit through mailings and newsletters.

The Polio Information Center was established, and a preliminary report was given by Harriet Bell at the Chicago Conference which heightened interest and increased the number of questionnaires, correspondence, requests for information of specific problems and referral to physicians and services.

For the past year, it has been funded from a grant received by Harriet Bell from the Wonder Woman Foundation. A grant proposal is being developed. Warner Communications contributed an Atari 800, complete with printer, which will be used for word processing, compilation of lists and storage of information for referral.

Harriet Bell reported the results of the Post-Polio Questionnaire to participants of the Second International Post-Polio Conference, and urged that polio survivors band together to form a network across the country. The Polio Information Center, the Texas Institute for Rehabilitation and Research and several other rehabilitation centers around the country are collaborating on a project to collect basic medical information on as many polio survivors as possible.

Some polio survivors who are experiencing physical difficulties are referred directly to Dr. Augusta Alba, New York, who arranges a physical evaluation for them at Goldwater Memorial Hospital. A list of physicians who are familiar with problems associated with polio has been started. Referrals have been made in several states.

The Polio Information Center could be viewed as a conduit for international exchange of information in all areas specific to polio. This can be gathered through the results of research, publications and reprints of articles. Care and treatment would improve.

Looking at the worldwide picture, it becomes apparent that polio is rampant in our neighboring countries--Central and South America--and in Third World nations just a few jet hours away.

Networking has begun--a polio survival group in Buffalo, one in Indianapolis, another in Morales, Texas, and yet another in California have made themselves known to the Polio Information Center.

In the future, the Center hopes to continue its work and serve as a conduit in the dissemination of information and resources.

# Chapter IV

## Conclusions and Recommendations

The first part of this paper was devoted to a history of the men and women who contributed with their research to the development of the vaccine which virtually wiped out polio in this country.

The key word in the preceding sentence is "virtually." Perhaps because epidemics in this country are "virtually" a thing of the past, immunization programs have not been enforced. It is important to note that outbreaks of polio have been reported in Texas, along the Rio Grande River, and in the Amish country in Pennsylvania, where immunization was refused.

And World Health Organization statistics indicate that, although several vaccines are available, every year polio reaches epidemic proportions in some countries, namely India, Ghana and other developing nations. With jet travel, every country in the world, including those with incidences of polio in epidemic proportions, is only a few hours away.

Among individuals who have survived polio, the television program "Prime Time Saturday," NBC, July 5, 1980, and occasional articles, reaffirmed the physical problems people were experiencing. A post-polio questionnaire seemed a viable way to determine the needs and problems of polio survivors.

The publication of the post-polio questionnaire in several major publications with disabled population readership yielded the largest number of names and information for a data base. This was the beginning of the Polio Information Center, which now operates as a referral center and catalyst for research.

The two International Post-Polio Conferences, in 1981 and 1983, marked the first worldwide interest in post-polio survivors.

It is recognized that polio is endemic and epidemic in many areas of the world, there may be as many as five million new cases each year. In view of the fact that there are vaccines available, this is a crime.

It is recommended, therefore, that:

1. The World Health Organization make a study of the distribution and effectiveness of polio vaccination programs.

2. Each state pass a law providing for immunization against polio for all children before they enter school.

3. A Federal law be passed ensuring immunization for all travellers going in or out of the country.

4. The Department of Health and Human Services and the Office of Handicapped Research supply funds to qualified researchers to study the present problems.

5. The Veteran's Administration create a division to assist polio survivors who were in the military.

6. Medical school curriculums include information about post-polio syndrome.

7. Materials be made available to physicians and other health professionals.

8. Polio survivors can turn to the Polio Information Center to get the specific answers to their questions.

9. The March of Dimes, which now supports birth defects, go back to caring for polio survivors as part of their responsibility.

10. The National Easter Seal Society assume, as part of their work, services for polio survivors.

11. People who survive polio join together in supporting one another with information, resources and spirit.

This paper has presented the results of two questionnires and the development of the Polio Information

Center. It consists of extensive personal research as well as reporting on the global incidence of polio.

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# Appendix A

PLEASE SEND THIS QUESTIONNAIRE TO AT LEAST **THREE** POST-POLIO PEOPLE YOU KNOW.

# Post-Polio Questionnaire

The personal experiences of people who had polio will give a clearer picture of some problems now being reported, and their solutions. A team of people who are post-polio created this questionnaire. You can help us all by returning this questionnaire immediately. Send it to: HARRIET BELL, 510 MAIN STREET, A446
ROOSEVELT ISLAND, N.Y. 10044

Name Telephone
Address Age
Education
Work Experience

1. Year you contracted polio
2. Type or types: Cerebral ☐ Bulbar ☐ Spinal ☐ Respiratory ☐ Don't know ☐
3. Physical Involvement: Muscle Weakness ☐ Para ☐ Quad ☐ Ambulatory ☐ Wheelchair ☐ Braces ☐ Respiratory Aids ☐
4. Hospitalization: Yes ☐ No ☐ Length of Stay
   If yes, which one
5. Treatment: Kenny Hot Packs ☐ Physical Therapy ☐ Occupational Therapy ☐ Psychological Help ☐ Respiratory Therapy Yes ☐ No ☐ Tank Respirator ☐
   Cuirass ☐ Monaghan ☐ Huxley ☐ Emerson ☐ Other Don't know kind ☐
   Multi Lung ☐ Thompson ☐ Bantam ☐
   Eureka Blower ☐ Rocking Bed ☐
6. Were you weaned from the respirator How long after inception of polio
7. Did you receive either Salk or Sabin Vaccine AFTER contracting polio: Yes ☐ No ☐ Don't know ☐
8. At what point did you feel you were rehabilitated
   Year
9. Did you return to the community: Yes ☐ No ☐
10. Did you remain in an institution: Yes ☐ No ☐ Which one
11. Have you been hospitalized since: Yes ☐ No ☐ For what
12. Have there been any changes in your physical condition: Yes ☐ No ☐

Shortness of Breath ☐
Dizziness ☐
Contractors ☐
Scoliosis ☐
Depression ☐
Numbness in Fingers, Toes ☐
Increased Weakness in Muscles ☐

Headaches ☐
Brittle Bones ☐
Anxiety ☐
Changes in Personality ☐
Interrupted Sleep Patterns ☐
Susceptibility to Respiratory Infection ☐
Others, please specify

Fatigue ☐
Fractures ☐
Blacking Out ☐
Gastrointestinal Problems ☐
Increased Need of Sleep ☐

13. Have you sought medical advice: Yes ☐ No ☐ When
    Where were you treated
    For which of the above

CONTINUED ON BACK

How

For what length of time

Medications

Presently in treatment: Yes ☐ No ☐ If yes, please specify

14. Did *you* suspect that these symptoms were related to polio: Yes ☐ No ☐
Because of something you saw on TV ☐ Radio ☐ Which program
Because of something you read in the newspaper ☐ magazine ☐
Did a friend share his/her experience: Yes ☐ No ☐

15. Did you share with your physician that your symptoms might be polio related: Yes ☐ No ☐
Was your physician receptive: Yes ☐ No ☐

16. Did your physician connect your symptoms with polio: Yes ☐ No ☐

17. Had the physician treated polio in the past: Yes ☐ No ☐ Epidemics of 40's–50's ☐

18. Do you think the physician sought additional information for your benefit: Yes ☐ No ☐ Don't Know ☐

19. To whom did the physician go for this help:

Were you helped: Yes ☐ No ☐ Don't Know ☐ How

If not, please comment

20. Did you have a rehab evaluation and readjustment: Yes ☐ No ☐ When
Where
Were you helped: Yes ☐ No ☐ How

21. What was recommended
Respiratory Aids ☐ Kind
Splinting ☐ Bracing ☐
Wheelchair Use ☐ Full Time ☐ Partial Use ☐
Other Equipment

22. What future resources do you think should be developed for your well being:

Thank you for your help. Please feel free to make additional comments and suggestions and to answer more fully any questions on another piece of paper.

If you want more questionnaires sent to you or to other people who are post-polio, send these requests with this questionnaire to HARRIET BELL, 510 MAIN STREET, A446 ROOSEVELT ISLAND, N. Y. 10044 This questionnaire may be xeroxed.

# Appendix B

February 1983

Dear Friend,

I am writing to ask for your help again. In September, I became a doctoral candidate and as part of my research, I designed the enclosed questionnaire. The information will add to the data already compiled about polio survivors.

My research focuses on women, specifically those disabled by polio, and the sharing of our mutual experiences can be of great help. I want you to know that although your name, address and other personal information is on the questionnaire, everything will remain confidential.

Please mail it back in a hurry. I will let you know the results.

Sincerely,

Harriet Bell
510 Main Street, A446
Roosevelt Island, NY 10044
(212) 223-0353

This questionnaire was designed to complete a study on disabled (polio) women and marriage. Please answer all questions, if applicable, and return immediately to:

HARRIET BELL
510 Main Street, A446
Roosevelt Island, NY 10044

..........................................................
..........................................................

NAME ________________________________ AGE ____

ADDRESS ________________________________________
Street City State Zip

URBAN Yes ____ No ____ RURAL Yes ____ No ____ TEL.( ) ________

AGE WHEN YOU CONTRACTED POLIO ______

ETHNIC BACKGROUND

American Indian ____
Asian ____
Black ____
Hispanic ____
White ____
Other ____

PRESENT MARITAL STATUS

Never married Yes ____ No ____
Married Yes ____ No ____
Number of marriages ____
If married, number of years ____
Was married, now separated Yes ____ No ____
Was married, no. of years ____ Separated, no. of years ____
Was married, now divorced Yes ____ No ____
Was married, no. of years ____ Divorced, no. of years ____
Widowed Yes ____ No ____

Was/is your husband disabled? Yes ____ No ____

EDUCATION

Less than high school ____
High school ____
Bachelor degree ____
Master's degree ____
Doctorate ____
Other ______________

FAMILY INCOME

$10,000 or under ____
10,000 - 20,000 ____
20,000 - 30,000 ____
30,000 - 40,000 ____
40,000 or more ____

## WORK

Do you work? Yes ____ No ____
Type of work you do (outside home) ____________________
Type of work you do (at home) ____________________
If presently married, does husband work? Yes ____ No ____
Type of work husband does outside the home ____________________
____________________
Type of work husband does at home ____________________
____________________

## HELP IN THE HOME

Housekeeper Yes ____ No ____
Home Attendant Yes ____ No ____
Baby sitter Yes ____ No ____
Other, specify ____________________

## FAMILY ACTIVITIES

Do you participate in civic activities? Yes ____ No ____
If presently married, does your husband participate in civic activities? Yes ____ No ____
Do your children participate in civic activities? Yes ____ No ____
Do you attend religious services? Yes ____ No ____
If presently married, does your husband attend religious services? Yes ____ No ____
Do your children attend religious services? Yes ____ No ____
Do you participate in recreational activities? Yes ____ No ____
If presently married, does your husband participate in recreational activities? Yes ____ No ____
Do your children participate in recreational activities? Yes ____ No ____

## FAMILY RELATIONSHIPS

Your relationship with your husband, if presently married, is:
Excellent ____ Good ____ Fair ____ Poor ____ Bad ____

Your sexual relationship, if presently married, is:
Excellent ____ Good ____ Fair ____ Poor ____ Bad ____

Your relationship with your children is:
Excellent ____ Good ____ Fair ____ Poor ____ Bad ____

## FAMILY RELATIONSHIPS (cont.)

Your relationship with your grandchildren is:
Excellent _____ Good _____ Fair _____ Poor _____ Bad _____

Your relationship with your parents is:
Excellent _____ Good _____ Fair _____ Poor _____ Bad _____

Your relationship with other relatives is: (specify) ____________________
Excellent _____ Good _____ Fair _____ Poor _____ Bad _____

## DIVORCE

Check all of the following which were reasons for divorce _____
separation _____

My disability _____
Money _____
Incompatability _____
Alcohol abuse _____
Child abuse _____
Drug abuse _____
Lack of privacy _____
Too much responsibility _____
Other ______________________________________________________
______________________________________________________

## COMMENTS

______________________________________________________________

______________________________________________________________

______________________________________________________________

______________________________________________________________

______________________________________________________________

HB/1/83

FROM: "proceedings of an international symposium" .... WHAT EVER HAPPENED TO THE POLIO PATIENT .... Chicago, Illinois .... October, 1981.

Correction .... Harriet Bell, Polio Information Center
510 Main St., A446, Roosevelt Island,
NY 10044

# SOLVE THE ISSUE

**Harriet Bell**

President, Polio Survivors Association,
Goldwater Memorial Hospital, New York, New York

Contracted polio, is quadriplegic, and is ventilator-dependent

As a result of an article in the Rehabilitation Gazette, which estimated that 250,000 people who had polio are still living, a post-polio questionnaire was designed by Harriet Bell and Florence Weiner of New York City.

Although they have worked with no financial support, data collection and analysis continue with the volunteer assistance of friends. Data are now being entered into the computer, but the number of variables may preclude clear conclusions.

However, certain trends are evident. Polio survivors are around 38 or 55 years of age, have a high education level, including many with advanced degrees, and feel isolated, deserted, or dropped. If they were weaned from respirators, they often show signs of shortness of breath, interrupted sleep patterns, and depression. Many people have gastrointestinal problems. The same medications are prescribed across the country. Polio survivors are looking for capable doctors. Those being trained at the present time are unfamiliar with acute or post-polio problems.

A central information resource center is needed, one that will serve polio survivors across the country.

* * * * * * * * * *

## Our Post-Polio Questionnaire

In the Rehabilitation Gazette, it was estimated that there are 250,000 people who may have had polio. There are 6 to 8 million children in this country who have not been inoculated. In the 1980 issue of the Gazette, Gini Laurie published a post-polio questionnaire by Florence Weiner and me, which was distributed to approximately 6,000 people across the country. There was very little response at that time.

Since then, there has been a tremendous response to this questionnaire. It has been disseminated by mailings throughout the country and by word of mouth. I am sure all of you received a copy yesterday.

We have done everything on a shoestring -- or really, half a shoestring -- because we have had absolutely no financial support. Volunteers help with the statistics. Everything has been done through friends who are interested in the people who have had polio.

## The Early Results of Our Survey

It is a little early to tell you what we have learned. The data are just going into the computer. I do not think we will ever have clear data, because there are too many variables. Each questionnaire is a story by itself. Some people write ten pages, some write two pages, and some people fill in only three questions. Each one is so different, we may never know exact percentages.

## Age Distribution

There are some very interesting things we do know. For instance, the majority of the polio-survivors are around 38 or 55 years old. Most of us were caught in the last polio epidemics just before the Salk vaccine. People were either young adults or very young children.

As we have heard, people who had polio tend to have a very high education level. Many, many people have advanced degrees; several are PhDs and several are MDs.

## Clear Emerging Patterns

Certain patterns are beginning to show, even without a computer analysis. For instance, when someone checks "yes" in answer to, "Were you weaned from the respirator?" most likely "shortness of breath," "interrupted sleep patterns," and "depression" are also checked.

We turn the page and it states, "I need a doctor but cannot find one." Many people realize that physicians now being trained, who have never been exposed to acute or post-polio, do not know how to treat polio survivors. Many have gastrointestinal problems. Many take the same medications. Many feel isolated, deserted, or dropped.

## Future of Our Survey

For our project, we did not apply for grants or other funding, believing that we must establish credibility first. After we have received at least 600 completed questionnaires, we will begin applying.

There appears to be a definite need for a foundation or national resource center where information could be gathered and disseminated to polio survivors throughout the country.

# Appendix C

POLIO INFORMATION CENTER

NEWS

VOLUME 1, NUMBER 1 SPRING 1983

# Polio Information Center Continues to Thrive

At the First International Polio Conference: "Whatever Happened to the Polio Patient?" held in Chicago, May, 1981, Harriet Bell announced the establishment of The Polio Information Center.

The Center grew out of an awareness of the need for a resource for people who had polio and were experiencing medical problems. A post polio questionnaire, developed by Harriet Bell and Florence Weiner, revealed that there was a similarity to the difficulties, no matter the age, date of onset, or the type of polio contracted.

In addition, the questionnaire reported a growing frustration in finding physicians who had experience treating people who had polio.

Shortness of breath, muscle weakness, interrupted sleep patterns or the need for additional sleep because of exhaustion, depression, dizziness, pain, were some of the complaints brought to physicians who did not connect them with polio.

A segment on *CBS 60 Minutes* validated the concerns when two post polio survivors described the problems they were experiencing.

For the first time since the major epidemics of the 1940's and 1950's, attention was devoted to polio.

The Salk vaccine, introduced in 1955, wiped out polio epidemics in this country, and, indeed, the consciousness about polio.

For the estimated 250,000 survivors of polio in this country, and the millions of people in other countries — just a few jet hours away — who continue to contract polio, the disease is not a thing of the past.

The Polio Information Center serves as a resource to people who had polio, their family, and professionals.

Located at 510 Main Street, Suite A 446, Roosevelt Island, New York, 10044, the Center fulfills a long awaited need. ●

Photo by Chris Sheridan

*Harriet Bell answers a request for information.*

# Polio Information Center Sets Goals

The Polio Information Center has made a commitment to the following:

- To continue to publish this newsletter,
- evaluate and publish the findings of the post-polio questionnaire,
- make available polio related materials,
- establish the need for a hotline,
- establish the need for a nation-wide referral service,
- encourage research in the following, but not limited to: the relationship of weaning from the respirator and current respiratory dysfunction, a study of drugs that may be contra-indicated for people who had polio, research in relevant rehabilitation engineering,
- establish referrals for medical, psychological and social services,
- maintain a permanent computerized file of individuals who had polio. ●

# Margaret Pfrommer on Rehabilitation Engineering

Northwestern University Engineering Program, where I have worked for the last ten years, is one of about a dozen similar programs researching and developing technical aids for people with a physical disability. The attempt is to apply technology to the needs of the community. The engineering department is made up of engineers, as well as disabled citizens, doctors, therapists, social services people, vocational counselors, manufacturers and developers.

More and more disabled consumers are asked to test and critique the equipment, and have become a vital part of the program. Often the information of someone who uses the equipment will contribute to a professional rethinking a project. This is not always the case, but it is becoming more frequent.

Some professionals feel very strongly, for example, that if you can wheel your chair you should do it. I don't agree with that because there is an awful lot of energy going into wheeling your chair and not much left for anything else. It depends on the limits of your function, how much energy you are expending. If you can wheel your chair and still carry on all other activities then perhaps that is something you should do.

Technical aids ought to be used to make your life easier and enable us to do other things. If you have a limited amount of energy I think that should be considered.

Rehabilitation engineering has enable people to work who have not been able to before. Disabled people are more and more realizing that they are not getting the answers from the trained professionals without working with them.

We need, however, to put technical aids in perspective, computers especially. They are devices that are poor replacements for what has been lost in terms of physical funtion. We can't demand or expect too much from them yet. They are really gadgets, nice mechanical aids which we still expect too much from.

To find out information on rehabilitation programs you can contact the Rehabilitation Engineering Society of North America in Bethesda, Maryland. The National Institute of Handicapped Research, Department of Education, Washington, D.C.

You have to find the people who are taking the technology and applying it, and you have to look high and low for them.

The National Rehabilitation Information Center (NARIC), 4407 Eighth Street, NE, The Catholic University of America, Washington, D.C. 20017, is an excellent resource. •

## Future Resources for Well Being

The post-polio questionnarire included the question, "what future resources do you think should be developed for your well being?" These are some of the answers to that question.

"They should have a hot line where we could call for help."

''I certainly would like to find a doctor who knows something about polio. The ones I know have never seen a post-polio person and they don't know how to treat me."

" I'd like to see a study done on the drugs that are prescribed for us."

" Wouldn't it be interesting to see the results of a study on the children of parents who had polio."

" I'm 65, mother is 85, and she is still taking care of me. My pension can not pay for attendant care. What's going to happen to me?"

" I seem to be fatigued all the time. But I can't sleep either. There are times when I have shortness of breath. Where can I get a respiratory evaluation? What should the evaluation consist of?"

" I've written the March of Dimes because I need a new wheelchair. If they say no again where do I go?"

" I was weaned from a respirator thirty years ago and there is something wrong with my blood – they told me my $CO_2$ was high. I'm very tired. My psychiatrist thinks it's all in my head. I wonder about this."

" I walked away from polio thirty five years ago. All of a sudden I'm having a lot of problems. Could my polio be coming back again?"

" Am I the only one who is having these symptoms?" •

# Highest Award to Disabled Woman

On November 21, 1983, Harriet Bell received an award and grant given to her by the Wonder Woman Foundation, created to commemorate the 40th anniversary of the heroine, Wonder Woman, published by D.C. Comics, the award was given to her for her work as a health advocate. The grant has been used to fund the work of the Polio Information Center for this year. The award was the highest honor received by a disabled woman for making a significant contribution to society. •

# As I See It

by Tom Clancy

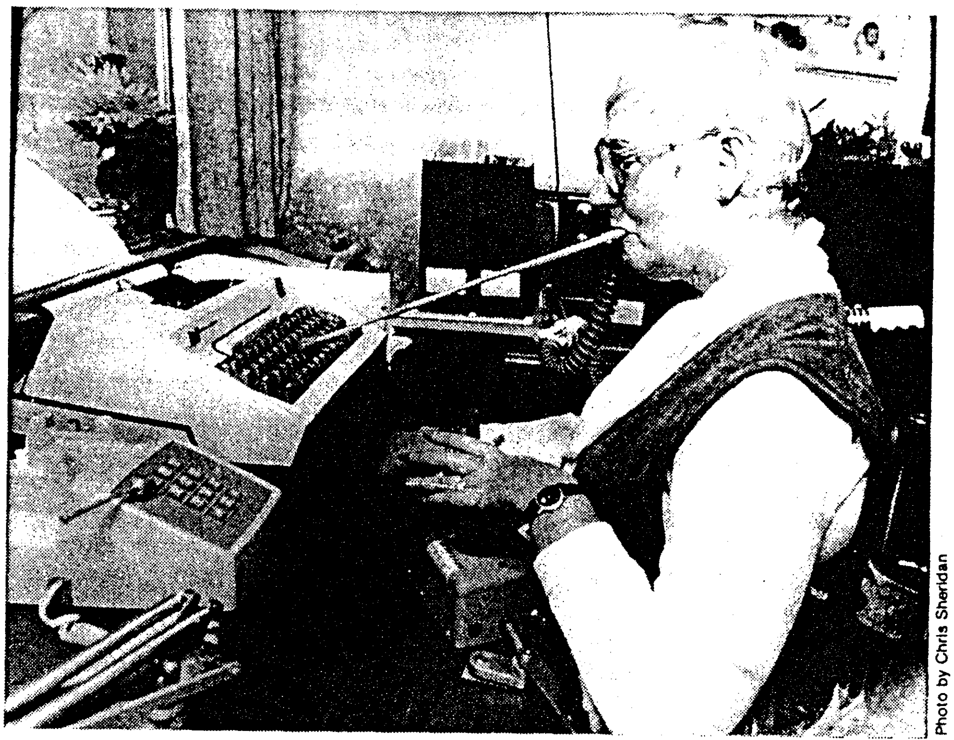

Photo by Chris Sheridan

*Keeping in touch adds a personal touch at the Polio Information Center.*

Most of us if we think about it have phases in our life and the first phase of my life was pre-polio – and that included a wife and a child, a pedestrian kind of job and hope that something better would develop. Then suddenly everything changed. There was no more physical capability. My biggest job was trying to stay alive and then tying to figure out what to do with what I had left. Times have changed a little bit since then, but at that time there was really not too much optimism for those of us who were really hit hard. I moved from hospital to hospital. There was no way to get back into law school. One of the things we always looked at were two kinds of people sitting in hospitals – those who looked out the window and those who believed that something better could happen. If you kept your head straight and tried to dream a little you could believe that one day things would change. It took me almost 16 years and a couple of false starts along the way, it also took some legislation and some awareness in the country that maybe dis-

*continued on page 4*

# Physician's Corner Guest Column

by August Alba, M.D.

**Question 1:**

For the past two years, I have been experiencing increased fatigue and difficulty in sleeping. I saw my physician and he checked my $CO_2$ and it was ok. What do I do now?

**Answer 1:**

You must take three steps. 1) If you have weakness of the trunk, the work of breathing can cause fatigue and difficulty sleeping even though your $CO_2$ is still normal. See either a chest internist or physiatrist with training in the pulmonary rehabilitation for further evaluation; 2) If your breathing is normal or near normal, post polio quadriparesis per se can cause increased fatigue and difficulty sleeping. Your physiatrist with the help of work capacity testing should be able to help you set limits to your activity within which you will experience fewer symptoms; 3) Fatigue and insomnia are nonspecific complaints. You must also have a thorough medical examination to determine whether there are other causes.

**Question 2:**

I live in the midwest and have trouble finding a doctor who knows anything about polio. I have not seen a doctor in six years.

**Answer 2:**

The Rehabilitation Gazette with headquarters in St. Louis, Mo., may be able to give you the names of knowledgeable physicians in your area. The nearest university medical center should have orthopedists/physiatrists who are able to help you.

**Question 3:**

I read in the report of the last polio conference that you are available for consultation and examination. Where do I go to see you? If the physicians are willing to treat me, can they call you for specific respiratory information? Can they call you for other aspects of polio?

**Answer 3:**

Contact the Howard A. Rusk Respiratory Rehabilitation Center at Goldwater Memorial Hospital, Roosevelt Island, NY 10044. Physicians can call me at the hospital for respiratory information and for information regarding other aspects of polio.

**Question 4:**

Does Valium affect my breathing? My physician prescribed this for anxiety and depression.

**Answer 4:**

Injectable Valium can affect breathing. Small amounts of Valium by mouth should not affect breathing unless it is taken with other medications or alcohol which depress respiration, or unless the person is very ill, elderly or with very limited pulmonary reserve. ●

# As I See It

*continued from page 3*

abled people did have a place and something to contribute. And so I left the hospital that I was sitting in and moved back to the rehabilitation process, got some education, found a wife, found an apartment, found a job, went to work. The first thing I had to do of course was to find a way to get to the door of work because curb cuts were pretty unheard of in those days and motorized chairs were something that did not go uphill. I have spent the last 16 years, almost another one-third of my life working in a job that I enjoy. There have been a lot of problems along the way, difficult problems, emotional problems, but most of all I guess we can all keep trying to draw the line. Data processing is the kind of work that maybe should have been available when I was young. Now it is the kind of thing where I can be functional and have a job that uses my skills and takes advantage of them, where I can earn my pay.

About 7 or 8 years ago I ran into my first encounter with this polio syndrome. Back then it was just called trouble. I had been mostly respirator-free for many, many years and then suddenly I couldn't breathe at all. I spent 3 months in the hospital never knowing what was really going on. I suppose in some ways it would have been tempting to forget the whole thing, but there is some kind of a drive built into you that tells you to get out, get started, put your life back togethher and go to work.

There is a lack of knowledge, a lack of awareness that something is going to happen and it almost did me in and took away some of my friends. I think that these conferences and everything else that will draw attention to and try to define what is happening are very valuable because the longer I've been around I suspect that polio may not have been all a bad thing. It is possible that many of us that got polio have something to offer the world and it is also quite possible that the world hasn't picked up everything available from us.

I would like to see an answer to this phenomenon that is going around because I think it will provide answers in many other areas for the future. I'd like to see the government really interested in those of us who have spent many years keeping ourselves alive and now need some kind of help again. The first time maybe it was more dramatic but now it is just as serious. I would like to see some real definitive ansers on what is happening. I would like to see more interest. I would like to believe that the government cares more about keeping us functional and operational than maintaining us. Most of all I would like to see a different interest in the whole subject from a very high level. ●

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**I would like to be part of the work of the Polio Information Center.**

☐ I have completed the questionnaire.

☐ I will complete the questionnaire, and return to you immediately.

☐ In the future, I will supply any additional information if requested.

☐ I would be willing to distribute the questionnaire to people I know.

☐ I would like to contribute articles for consideration to the Polio Information News.

☐ I would like to submit photographs to the News for consideration.

I would like to support the work of the Polio Information Center

$1_________ $10_________ $25_________ $100_________ other_________

Please clip and send to: Harriet Bell
Polio Information Center
510 Main Street, Suite A 446
Roosevelt Island
New York, New York 10044

# Appendix D

## Manitoba

Several studies of polio survivors are in progress. A report on the Manitoba Conference follows.

Three quarters of a million people lived in Manitoba, according to the 1951 census, with forty-five percent in Winnipeg and the others scattered throughout the province. In 1980, Dr. Joseph Kaufert, a polio survivor, decided to study this population to determine their needs and attempt to improve their quality of life.

Polio posed not only a terrible threat to life and limb, but an economic threat for families. The comprehensive public hospital insurance and health insurance available today in Canada had not yet been developed. There were no home care programs in the 1950s, and there was a great shortage of respirators. Only old, wooden respirators, charitably donated many years before, were found, unused and deteriorating. A total of 2300 polio cases were reported in 1953, representing an incidence of over 300 per 100,000 population.

Although some individuals had to remain hospitalized until the present time, most polio survivors went home and were cared for by an innovative home care program provided by the government.

According to The Honorable Mr. L. R. Sherman, Minister of Health, Government of Manitoba, the polio epidemic provided an opportunity (an unwanted one, to be sure, but nevertheless an opportunity) to review and improve methods of treatment of cases with bulbar and respiratory involvement.

Preventive strategies during the epidemic were based on the work of Dr. W. Hammond of the University of Pittsburgh with gamma globulin, which, when given to children, seemed to prevent the development of paralysis and lessen the severity of the attack.

> The 1953 epidemic was the greatest in number of cases of death, and severity of paralysis in the history of any North American urban population of over 200,000. One hundred ninty (190) cases were treated in respirators, and many of them required tracheotomies and suction. Eighty-nine (89) persons died during the epidemic, representing a case fatality rate of 3.7 per 100,000. This low fatality rate is attributed in part to the quality of care given, and the physicians, nurses, technicians and volunteers who gave untiringly of themselves during the epidemic. (Respiratory Polio Symposium, 1980, p. 82)

At the present time, a follow-up study of the great epidemics is being conducted. 100,000 questionnaires have been completed and the information compared with statistics from 1953. The designers of the program believe that the lessons of polio can be applied to the rehabilitation of many other conditions.