

PPASS Times

Newsletter of Post Polio Awareness & Support Society of MN

March - April 2002

Vol. 3, Number 2

From Where I Sit

By Jane St. Onge, Chair

Spring Ahead - It's that time of year for beginnings, renewal and growth . . . you know, Spring. Closets get hoed out, lightweight cottons replace those well worn sweaters and warm socks. Longer, warmer days bring us out of our shells. And time flies even faster than ever, it springs ahead.

Daylight Savings Time doesn't have anything on PPASS MN. We both are springing ahead. Our members' positive response to our recent pledge drive shows our commitment to growth. Non-profit status will encourage tax free donations that can be used to get the word out about PPS. And that's a good thing.

Thanks to our PPASS meetings and our newsletters, I have learned much about Post Polio Syndrome. You probably feel the same. Getting this information out into the community would give us the potential to help others who might have PPS, or who might have patients that have PPS.

Because of the limitations PPS puts on our stamina and mobility, it seems we are often needing help from others. The mutual support we give each other at our group meetings feels good because we

are both giving and receiving. Reaching out in to the community to create awareness and understanding is another way for us to give.

Yes, it's that time of year for beginnings, renewal and growth . . . you know, PPASS MN.

Group Happenings

By Larry Kohout

Our March meeting continued the discussion of the Polio Personality and type A behavior. Rob Olson, our facilitator, helped us look at some of the behaviors that continue to play a part in many of our lives. These behaviors can be both positive and negative at the same time.

Behaviors that allow us to focus and prioritize and organize can be very beneficial as they help people be successful in a business environment. However, that same behavior can cause us to stick at something far too long. When we ought to be taking a break and taking some time to rest and recuperate, the same driving behavior can cause us to keep on keeping on. Obviously, in this second situation the behavior has turned into a negative in terms of our health and well being.

During this same meeting Dick

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Not For Profit Fund Raising Drive

By Larry Kohout

From early in our history it has been our goal to become a non-profit corporation. Recently, under some pressure from member Dick Baumer, the executive committee began a serious pursuit of this goal. Baumer agreed to lead the effort, and he found a company here in the Twin Cities which specializes in helping organizations achieve this goal. Management Assistance Program for non-profits (MAP) exists to guide organizations in creating the Goal and Mission Statements and Charter Documents needed to become a corporation and then creating the budget and goals needed to be granted the tax exempt status by the IRS.

In setting up a budget, we determined that we need \$350 for the fee to MAP, another \$70 fee when applying to the state to become a corporation, and a \$150 for the IRS when we apply for tax exempt status under rule 501 (c)(3). This came to a total of \$570 and was our original fund raising goal. After the fund raising got started we suddenly found ourselves in the happy po-

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Group Happenings

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Baumer made a pitch for getting our group to become a not-for-profit organization. Baumer works for ADC and is aware of corporate funds from ADC that could be made available to PPASS MN if we were a not-for-profit corporation and sanctioned under rule 501(C) (3) of the IRS code. He also found that a company called Management Assistance Program for non-profits (MAP) will provide us the guidance we need to achieve this status.

Our executive committee met and decided that we need to go after this status in order to be able to do the fund raising needed to achieve several of the goals we have outlined in our Goal and Mission Statements. Baumer has volunteered to lead this effort. Following the March meeting we sent out the message to all members asking that people pledge to donate whatever amount they felt they could afford. - Editor's Note - See article on page 1 -

The April meeting was devoted to a presentation by Steve Hanson of Midwest Medical, one of the local Durable Medical Equipment Companies in the Twin Cities area. Steve brought in literature on all the different mobility devices that exist and talked about each of them and answered questions from the group about mobility devices.

One of the issues he talked about was the weight of manual chairs and the impact they have on peoples shoulders, arms, and hands. Hanson, who owns a spinal cord

injury, is using a chair made of titanium rather than aluminum or steel. His chair is a good 25 pounds lighter than some of its closest competitors. Not only does the titanium chair take wear and tear off his arms, it also is more flexible and so absorbs some of the shocks associated with rolling a chair over stone floors and the expansion joints in sidewalks.

Another piece of equipment that was discussed was a standing frame. This is a device that supports a person's legs and allows them to stand upright. Although they work in different ways they all have some mechanism for moving a person from a sitting position to a standing position and then keeping them in this position for a prescribed length of time. Most of the standing frames work with a hydraulic lift

that you pump to pull yourself into the standing position. There are a couple of frames that have an electric lift to assist people who do not have sufficient arm strength to operate the hydraulics.

The act of standing has many benefits that the health care industry has been slow to recognize. One of the major benefits is to maintain bone density in a person's legs, hips, and spine. When an individual does not stand and support the body's weight, the legs, hips, and spine tend to decalcify quite rapidly. There are a number of us in the group who are taking medication for osteoporosis. Hanson said that he has been using the standing frame for at least a half hour per day ever since his injury and that he has been able to maintain his bone density.

Another benefit of standing is that it promotes better overall health. It improves circulation, bowel, and breathing functions. All of this seems obvious when you stop to think about it. Unfortunately, I never stopped to think about it and am now paying the price.

Midwest Medical also provides repair services for all these items, either in their shop or in your home. They do not, however, sell the lifts needed to get some of this equipment into a vehicle and they do not handle things like stair lifts. They mentioned a company called Complete Mobility, which is located in Roseville. Complete Mobility handles the kind of equipment needed to get you in and out of your vehicle.

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Guest Speaker

On May 13th Margaret Hull, former psychologist at AtlantiCare Behavioral Health will be our guest speaker. Did you ever struggle and struggle to do something that other people find easy? When you finally got it done, did you have that rush of victory? That's what keeps a lot of us going.

Margaret Hull, Ph.D., and member of PPASS MN will talk to us about "The Joys of Overcoming Obstacles." She will share with us some of her experiences in overcoming polio obstacles, with the help of a wonderful family, supportive friends, and the kindness of lots and lots of strangers. She will tell us about struggling through college and graduate school in a wheelchair in the days when accessibility was probably not even a word yet, let alone a fact.

At AtlantiCare Behavioral Health, she did individual, group, and family psychotherapy with all kinds of people, but specialized with the seriously mentally ill. She took special pleasure in training budding therapists and sharing the perspective gained from all that struggling. In her talk she will be getting us all in touch with the joy to be gotten from our own overcoming of obstacles.



Not For Profit Fund Raising Drive

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sition of having more than \$600 pledged. We then decided to include a 20% (\$114) contingency fund taking our total to \$684 and then scale back everyone's pledge by the percentage that the pledge drive came in over our \$684 goal.

When we announced this intention at the April meeting we were happily surprised to find that by unanimous vote of those present they wanted us to collect the full amounts pledged and use any additional money to get started on some of our projects. With the publication of this issue of the newsletter our drive is officially closed. We stand at a grand total of \$1,025 pledged. We are all delighted and somewhat in awe of the generosity of our membership.

Baumer and the executive committee of St. Onge, Baxley, and Kohout, have the first appointment with MAP on Tuesday April 23. After this we will begin to appreciate the amount of work it will take to achieve our goal. Our intention is to create PPASS as an umbrella organization that will be the central information repository and fund raising organization for a group of inter-related support groups around the state. We have already talked with someone in Guthrie Minnesota who is interested in starting a group in the Bemidji area.

Another project is the recently completed first pass at putting together a team of medical professionals who are knowledge-



able about PPS and willing to stay abreast of developments in the field. Our first pass has assembled a team of 17 physicians of various specialties, four orthotists, one chiropractor, and one psychologist, all in the vicinity of the Twin Cities. We are currently assembling the first package of medical information to be mailed to these people.

We will continue to keep you informed of our progress on the Not For Profit status as well as the

Second Group Has Started

By Larry Kohout

A second support group meeting has started and is meeting on the forth Monday of the month. The group meets from 1:00 to 2:30 PM at Independence Crossroads (IC) office 8932 Old Cedar Lake Ave. So. in Bloomington. This group is focused only on support and is being facilitated by Rob Olson. If you are in need of more support don't pass up this opportunity.

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Second Group Has Started

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Olson has been facilitating our second Monday meetings since April of 2000. Olson, who works for IC, is also available for individual, one on one counseling sessions. Independence Crossroads is one of the first independent living centers in the Twin Cities area and has been providing services to handicapped individuals in Hennepin County since 1976. Olson can be reached at (952) 854-8004 or (612) 713-0849. All IC services are provided at no charge.

International Art Show

From Sister Kenny Post Card

You are invited to attend the Gala Grand Opening of the International Art Show by artists with disabilities. The Grand Opening occurs Thursday April 25 and runs from 5:00 to 8:00 PM. The show runs from April 25th through May 22nd.

This is the 39th annual Sister Kenny Art Show and it is held at the Abbott Northwestern Hospital at 800 East 28th Street, on the 2nd Floor, in the Sister Kenny Institute.

Both parking and admission to the show are free. Regular exhibit and sale hours run through May 22nd. Weekday hours are 9:00 AM to 5:00 PM, and weekend hours are 10:00 AM to 4:00 PM.

For more information call (612) 863-4463.

What's Coming Up?

By Larry Kohout

Our program committee, composed of Baxley, Fischer, Jandt, and Patrick, met after our April meeting and finalized their plans for our meetings for the remainder of the year. Here is what they have laid out from us:

May 13th - Speaker, Margaret Hull Ph.D. - The Joy of Overcoming Obstacles

June 10th - Summer Picnic

July 8th - Sharing Session - Hitting the Polio Wall

August 12th - Sharing Session - Just Say No

September 9th - Tentative - Speaker - Disability Rights

October 14th - Sharing Session - Coping Styles - What Ever Works

November 11th - Winter Holiday Party

December 9th - Sharing Session - Caring For Your Care Giver

Thanks Program Committee!

Sister Kenny Goes to Washington: An Unorthodox Nurse, Polio, and Medical Politics in Postwar America

By Naomi Rogers, Ph.D.

The following article was originally published as part of a Seminar Series of the New York Academy of Medicine in February 2000. It is reproduced here by the gracious permission of Dr. Rogers. It is Dr. Rogers intent to publish a book about Sister Kenny and she continues to

search for people who knew her and were treated by her. If you feel you have information along these lines you can contact Dr. Rogers by E-mail at naomi.rogers@yale.edu or by postal mail at:

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In May 1948 Sister Elizabeth Kenny went to Washington, D.C. for the first time. Kenny, an Australian nurse who had developed a new and controversial method of polio therapy, had been invited to appear as a witness before a Congressional committee investigating scientific research policy. Kenny praised a proposed National Medical Research Foundation to fund research into cancer, polio and degenerative diseases which would be directed by an advisory committee made up of physicians and lay people. And she thoroughly enjoyed her opportunity to challenge officials of the National Foundation for Infantile Paralysis (or March of Dimes) who were lobbying against the inclusion of polio in any such agency.

The struggles between Kenny and the National Foundation were not just over whether and how the government should fund polio research. Kenny was challenging orthodox medicine to admit her polio treatment was superior to standard care, and to see her as an expert on polio therapy and science. Calling Kenny as a Congressional witness clearly indicated that she was considered someone

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whose advice could and should be sought in the public debate over the shifting structure of federal health and science policy. Significantly, until the expansion of the National Institute of Health in 1948 and 1949, the National Foundation -- a private philanthropy that raised money for braces, crutches and iron lungs, for polio patient care, and for the training of health professionals -- was the largest organization in the United States funding scientific research, particularly the study of viruses. In February, a few months before these hearings the respected journal *Science* had published a controversial analysis of the geographical maldistribution of research funds (favoring elite Eastern universities) by the scientific advisory boards of private philanthropies, concluding that "our top scientists are no more able to provide equitable distribution of funds at their disposal than are the politicians they have so castigated."

If the distribution of research funds were so politicized, despite scientists' reliance on objective peer review, perhaps a government agency with lay representation would be more equitable and efficient. Further, the national debate over the federal government's role in health care and research planning was infused with partisanship, a kind of populist ideology for democratizing the coordinating bodies. In 1945 a North Dakota Senator suggested that the federal government establish a national polio clinic, run by a board made up not of physicians but of "persons who have had infantile paralysis and have been treated for such disease

in accordance with the methods discovered and practiced by Sister Elizabeth Kenny."

This paper (which is the basis for a chapter in my larger study of Elizabeth Kenny and American medicine) will ask: Why Kenny? Why Washington? And what did an Australian nurse have to offer the public debate over the direction of federal science policy in the Truman years?

Why Kenny?

By 1948 Sister Elizabeth Kenny and her method of treating patients paralyzed by polio had earned a distinctive place in American medical and popular culture. In a 1945 Gallup poll, for example, 52% of Americans recognized Kenny and the Kenny method; and two years later, the only women ranked in a Gallup poll on the most admired living people in the world were Eleanor Roosevelt (6th) and Sister Kenny (9th).

The story of Kenny's career in Australia had become a familiar tale. Born in New South Wales in 1880 (although she claimed it was 1886), the daughter of an Irish immigrant farmer, Kenny had "discovered" a way of treating polio while working as a private duty nurse in the isolated Queensland bush. In what she later realized challenged standard medical care of the disease, Kenny found that wrapping affected muscles in heated blankets and using muscle therapy as early as possible helped prevent and correct most deformities. During the 1930s, despite two government commissions expressing doubts about the value of her work, she established nine clinics in Australia, all supported by municipal politicians, public health officials and members of the public. Her success and her publicized

rejection of orthodox polio care antagonized many Australian physicians, especially orthopedic specialists. In 1940 a small group of sympathetic Queensland physicians urged her to go to the United States, hopeful that she would find an easier path to medical glory or, at least, to achieving her goal of altering mainstream polio therapy.

In North America, epidemic polio was a more significant public health problem than in Australia, President Roosevelt had himself "conquered" the disease, and a new philanthropic agency devoted to polio rehabilitation -- the National Foundation for Infantile Paralysis -- had recently been established. While Kenny has since faded from public memory, along with much of the public's fear of and fascination with polio, Kenny was a prominent figure in 1940s America. She was featured in newsreels and national magazines, and her life and struggles to gain acceptance for her work were the subject of a 1946 Hollywood film directed by Dudley Nichols and starring Rosalind Russell. Kenny produced her own documentary films, one of which was screened at her Congressional appearance in 1948. In 1950 Congress passed special legislation honoring Kenny by allowing her "unrestricted entry" (a lifetime visa-free passage across U.S. borders), and in 1952 (a few months before her death) she was chosen in a Gallup poll, ahead of Eleanor Roosevelt, as the most admired woman in America.

When Kenny had first arrived in 1940 Basil O'Connor, head of the National Foundation, and Morris Fishbein, the AMA's powerful general secretary, had both initially rebuffed her as yet another quack with a polio cure, but within a year

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their opinions changed, at least for a while. In Minneapolis, Kenny interested a few physicians at the University of Minnesota's medical school, in particular John Pohl, an orthopedic surgeon who directed the Infantile Paralysis Clinic at the city hospital. Kenny was offered control of a ward at this hospital and some beds at the university hospital, and set up a training course for doctors and nurses under the auspices of the medical school.

Pohl and his colleagues Miland Knapp and Wallace Cole published glowing accounts of the "Kenny method" in professional journals, including the *Journal of the American Medical Association (JAMA)* in 1941, supported by a positive editorial by the journal's editor Morris Fishbein. In 1943 Basil O'Connor wrote the preface to the textbook written by Kenny and Pohl, commenting that, although "in medicine it is not well to believe the eye alone," nonetheless "those who work in the laboratories with problems in histopathology, anatomy, and physiology claim that the major concept is reasonable and rational."

Within a few years, however, these relations had soured. In 1942 Kenny left Minnesota's medical school (although she retained the support of Pohl and other local physicians) and set up her own separate Kenny Institute with the help of the families of local patients and the Minneapolis mayor Marvin Kline. The National Foundation had funded Kenny's training course when it was under the supervision of the medical school,

but after she became the director of her own Institute this funding stopped, although the National Foundation continued its standard policy of funding any method of treatment practiced at any hospital in the country if approved by a physician. In 1944 Kenny established her own competing polio philanthropy, the Kenny Foundation, which gained millions of supporters and dollars, with the help of such patrons as Bing Crosby and Rosalind Russell. By 1948 six states had free-standing Kenny clinics, and many hospitals across the country employed doctors, nurses and physical therapists trained in the Kenny method.

Kenny not only intrigued American medical professionals, she gained popular interest in her role as a medical populist, confronting elite physicians and scientists with a "backyard discovery." Articles about Kenny with such titles as "Healer from the Outback" began appearing in popular magazines like *Reader's Digest* and the *Saturday Evening Post*. Science writer Victor Cohn at the *Minneapolis Tribune* gained national attention through his reports of her work. Kenny wrote two major texts directed to American medical audiences published in 1941 and 1943, and gladly gave interviews to lay reporters. Her 1943 autobiography was dedicated to the "Mothers of Mankind."

Kenny gained attention so quickly because her work dealt with a high profile disease, and filled the therapeutic vacuum around it. Since the 1900s polio epidemics in the United States had been growing more serious and more frequent. Although the disease remained a relatively minor cause of morbidity and mortality, in the minds of parents in the 1930s and 1940s it was

major threat to their children's health. Doctors were unable to predict, prevent or treat it, and victims were sometimes left crippled, sometimes miraculously unaffected. Kenny provocatively promised far more ambitious results that did most health professionals. Her goal was fully recovered movement; she proudly entitled her autobiography *And They Shall Walk*. Her definition of the disease -- as well as its therapy -- allowed for the possibility of successful therapeutic intervention, and to a great extent, transformed standard polio therapies -- especially splinting and surgery -- into symbols of a failed and even harmful clinical program.

Kenny's American success clearly drew on the widespread dissatisfaction with prevailing polio care which could be isolating and depressing for child and family. Child victims were sent first to infectious disease wards of their local hospital, kept in isolation until deemed non-contagious, and then, depending on the extent of their paralysis, sent back to their families or to a crippled children's home. Standard orthopedic care was strict immobilization, sometimes in a double-brace frame for many months. This therapy was designed to keep muscles in their "correct" positions but for growing children it often left them with deformities that no amount of orthopedic surgery could heal. Until Kenny politicized polio therapy, there were almost no scientific studies of polio treatments, and few hospitals employed more than a single physical therapist. Indeed, rehabilitation medicine, until it gained a national professional standing with Howard Rusk's care of disabled World War Two veter-

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ans, was largely considered women's work, often done by mothers at home. Polio research in this period centered around laboratory studies of the polio virus in the hopes of finding a vaccine; the development of polio therapy was left to individual doctors, nurses and physical therapists. Kenny, by comparison, took the training of therapists and the investigation of therapy seriously. She demanded professionally trained therapists, and she promised patients and their families recovery.

Kenny could have argued that her new method was the empirical contribution of a humble nurse which might usefully supplement standard polio care. This is not what she did. Rather than seeing her method as a progressive improvement, building on the work of respected polio therapy experts such as Boston orthopedist Robert Lovett and George Bennett, the medical director of Warm Springs, Kenny argued instead that hers was the opposite of orthodox methods, a revolution in understanding of polio. "The symptoms observed by me in the major part were diametrically opposed to those accepted through the medical world," she told the Congressional committee in 1948. "My contribution is not a treatment. I have discovered new conditions in the disease. Those conditions want investigating, and when they are properly investigated, something further can be done."

Here is an example of Kenny's own description of her theory and her teaching style. In 1943 she recalled her effort to teach a group of

physicians and physical therapists at the Minneapolis General Hospital three years earlier:

I did my best to explain that splinting would not take care of the condition. It might by the application of sheer force keep the patient's body straighter, but it prevented articulation and turned the muscle fiber into a useless, non-elastic mass. It seemed impossible for them to accept the explanation. At last, in desperation, I told them that if they wished to learn what I had to teach them, they must begin by understanding that the disease they were so familiar with simply did not exist; that the disease they had been treating was unknown to me, even as the disease for which I had developed a treatment was unknown to them. I added that if they wished to continue treating for symptoms with which they were familiar, then my lectures and demonstrations were a waste of time.

Numerous individual doctors, especially specialists in pediatrics and physical medicine, were drawn to Kenny when they saw patients overcoming what were considered unyielding deformities; nurses and physical therapists were impressed by the significant easing of patients' pain through the use of "hot packs" (moist heat) around affected muscles. Even when they found Kenny's textbooks confusing many were impressed by her charismatic fervor when they met her in person; a few even said she had "healing hands." But Kenny alienated many other health profession-

als by her arrogant confidence in herself, her abrasive clinical teaching style, and her clear disdain for those who, as she characterized them in her 1943 autobiography, "Have eyes but will not see." Even more frustrating for her medical audiences were the unfamiliar terms she used to describe her new concepts. She argued that muscles that appeared to be paralyzed after polio infection were in fact "in-coordinated," "alienated" from the nervous system and could be "reeducated" through careful muscle training. Even muscles that superficially seemed unaffected were in fact in "spasm" (a previously unrecognized condition in polio) and required treatment.

Nor was she content to simply say that her method worked; she believed she understood why. She argued that her idea of polio undermined the current medical understanding of the disease. "May I respectfully draw your attention to the fact that my contribution to medical science is not a method of treatment, but a new concept of the disease?" she wrote to one Philadelphia physician who had told her that his colleagues were beginning a study of her method. In the orthodox view of the 1930s and 1940s, polio was considered a disease of the nervous system. Based on research studies of experimental animals, relying on particular strains of the virus, virologists believed that the polio virus could grow only in neurological tissue, traveled through the body only through neural tissue, and injured mainly the brain and spinal cord. This research suggested that the virus damaged or destroyed connections between nerve cells and muscles, leading to paralysis. In Kenny's theory, polio was not a

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neurological illness but a systemic disease; the virus left most muscles not destroyed but in spasm, while their corresponding nerve cells remained simply inactive; thus, connections between nerves and muscles could be repaired through directed muscle therapy. Kenny, thus, argued that the whole orthodox concept of polio was incorrect; doctors did not understand the "true symptoms" of the disease and therefore treated the wrong disease. Kenny's emphasis on therapy convinced her that the symptoms of polio were polio; she did not deny that it was caused by a virus, but suggested that the virus did not only affect the nerves; but the skin and muscles as well.

Kenny rarely commented on the unresolved problem of polio transmission, but she was well aware of the conflicting theories held by American researchers: prominent culprits were food, ice cream, flies, and swimming pools. Nor had researchers confidently established just how contagious the disease was. Their uncertainty had left public health officials or ordinary physicians without many theoretical or practical resources to help calm a frightened public.

During the 1940s, however, some aspects of this picture began to change. Researchers began to see the virus as typically endemic in the population and as a systemic infection in the body. Epidemiologists at the Yale University Polio Unit found high concentrations of the virus in sewage systems of New Haven and New York City, suggesting widespread infection, and perhaps general immunity.

New serological techniques which allowed researchers to test population groups for antibodies demonstrated varying waves of infection and perhaps different strains of the virus. Virologists Dorothy Horstmann of Yale, and Isabel Morgan and David Bodian of Johns Hopkins were able to cultivate the virus in blood and in non-neurological tissue, work that culminated in the 1949 tissue culture study by John Enders' team at the Boston Children's Hospital which won the Boston group a Nobel Prize in 1954. These studies forced researchers to develop new ways of thinking about polio, and led to techniques for the production of safe polio vaccines, achieved during the 1950s by virologists Jonas Salk and Albert Sabin.

Kenny drew on none of this work explicitly, although she was aware of the intellectual turmoil faced by polio researchers. She was confident that her own concept of the disease would in its clarity and comprehensiveness -- in its attention to the virus and to clinical symptoms -- convince both the lay public and health professionals. Although Kenny stressed that her new concept of polio was as important as her new therapy, members of the public were most excited by the latter. The public found especially convincing Kenny's portrayal of orthodox therapy as nihilistic and harmful, as well as her claim that elite medical specialists, prejudiced against outsiders, were boycotting her work. Conscious that she challenged the accepted subservient role of nurses, she frequently quoted a Minnesota pediatrician who "informed me that if I had the letters 'M.D.' after my name, all would be well." What made her

especially angry were the refusals by many physicians, and by the profession at large, to accept her as a polio expert. At the 1948 hearings Hart Van Riper, the National Foundation's medical director, noted that, traveling around America during the previous summer's polio epidemic, while he had seen the standard "orthodox" care supplanted everywhere by Kenny's method, nonetheless "in many places this kind of treatment was not called 'the Kenny treatment,' since in minor ways it was modified by the physicians ordering it." The title of her treatment "the Kenny method" was being lost and her method was being "modified" by health professionals rather than being practiced only by properly trained therapists from either her Kenny Institute or another authorized institution.

Although Kenny attacked medical elites, including officials of the American Medical Association and the National Foundation, she wanted to be taken seriously by the American medical establishment. Kenny recognized the high and rising status of physicians in American society, and sought their approval. Throughout her life she retained the close friendship of a number of physicians, including the Minneapolis orthopedist John Pohl with whom she wrote her major text in 1943. And however unorthodox her ideas may have appeared, she was certainly never anti-science. On the contrary, she constantly called for scientific investigations of her work, and was very disappointed when the National Foundation refused to consider her Institute a research institute like the Rockefeller or the Pasteur Institutes. Kenny fervently rejected the accolades of groups

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clearly on the margins of medical orthodoxy. She refused, as she explained to one Philadelphia medical enthusiast, to associate with the "minor branches of medicine" such as osteopathy and naturopathy. At the 1948 hearings in Washington she told a Congressman (whose personal physician was an osteopath) that she had promised her Australian medical mentor Aeneas McDonnell "that I would keep with the duly qualified medical practitioner until he saw the light" for "I know that if I did veer out a little from the straight and narrow path, that the duly qualified medical practitioners would have nothing to do with me." What frustrated her was the lack of respect for herself as a scientist and discoverer so that she was unable to control the correct way to practice her method. But perhaps the opportunity to present her case on such a public politicized stage as the 1948 hearings would enable her to overcome this resistance.

Why Washington?

In January 1947 the AMA's Council on Pharmacy and Chemistry, a group founded in 1906 to try to coordinate clinical investigation, published its annual report in JAMA, a plea for greater appreciation and better funding of clinical research. "It does not seem to be generally appreciated that clinical research, if properly performed, is often as expensive as laboratory investigations," the Council remarked, warning that insufficient financial support "has resulted in the performance of poorly controlled and ill conceived investigations the data from which do not

advance the science of medicine, by reason of incompleteness and unreliability." The Council expected that the "future trends in research costs" would be met by "universities, foundations, commercial concerns or private donors" (and briefly mentioned "public funds"), and would require coordination by "some impartial central agency" like the Office of Scientific Research and Development and the Committee on Medical Research whose efforts had, during the recent war "resulted in great advances in medicine." Trying to establish professional control of the coordination of research, the Council had recently established a Therapeutic Trials Committee "for the purpose of assisting sponsors wishing to support research and investigators anxious to participate in worth while therapeutic research ...with less waste of both time and effort than is possible without some central coordinating agency." Between 1947 and 1950 members of this Committee privately debated the possibility of conducting a clinical trial of the Kenny method but could never agree on protocols or procedures.

The Council's 1947 report did not recognize that the federal government was becoming a major player in shaping the confusing quilt of medical research programs in peace-time. The experience of World War II had reinforced the notion that a government agency could easily and effectively direct research priorities and that such research, inspired by widely shared, unambiguous goals, would provide concrete solutions. The Cold War provided a new urgency for Congress to take a more active role in funding research. Thus, inspired by the war-time science col-

laboration that had led to the bomb, William H. Stevenson, a Wisconsin Republican Congressman, introduced his bill to establish a \$10 million "National Medical Research Foundation" in January 1947, telling Congress: "I was first prompted to think of this, as so many of you members were, immediately after the dropping of the atomic bomb and we found what could be performed by the cooperation of Government funds and the keenest scientific brains of the world."

When Kenny came to Washington, Congress was beginning a massive expansion in federal funding of scientific research. The American public, already impressed with the scientific achievements made during the war -- penicillin, radar, the atom bomb -- saw research possessing the potential to improve both the world and everyday lives. World War II, as historian Victoria Harden described it, "enhanced public belief that scientific research offered an endless frontier on which a happier, healthier life could be built." Not only did Congress fund post-graduate medical training through the 1944 GI Bill of Rights and hospital construction and renovation with the 1946 Hill-Burton Act, but it expanded the National Institute of Health (NIH) by adding the National Heart Institute in 1948 and the National Institute of Mental Health in 1949, and in 1950 established the National Science Foundation.

But who should direct this research and define its priorities? Where should it take place? And what place should private philanthropies have in directing its course? Before the Second World War medical research funding was dominated by various private organiza-

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tions who supported individual university researchers. After the war philanthropic groups organized around specific diseases made research rather than medical care and equipment a priority, and new private organizations were created with specific research goals. In 1946 Sidney Farber, a Harvard pathologist, established a children's cancer research society known as the Jimmy Fund; and reporter Walter Winchell created the Damon Runyon Memorial Fund for Cancer Research, named after a Broadway reporter, and used his celebrity connections to give cancer research a high profile. Officials of such organizations came to be seen as appropriate directors of federal research policy. Thus, as part of the debate over a national science foundation, Stevenson's proposed Medical Research Foundation -- which specified first cancer, then poliomyelitis, and then other "degenerative diseases" -- listed representatives of American Cancer Society and American Heart Association as possible members of the federal agency's advisory board.

Medical Politics

Proposals to create new federal agencies to direct medical research and to expand the NIH were enthusiastically received by a number of disease-oriented philanthropies, including the American Cancer Society and the American Heart Association. But one prominent critic was the National Foundation for Infantile Paralysis. The National Foundation did not deny that scientists needed government aid in addition to private grants, and its

appointment in 1946 of Harry Weaver as a new director of polio research demonstrated the organization's belief in centralized and coordinated investigation. Nonetheless, at a series of Congressional hearings in the 1940s, officials argued strongly that polio should not be specified in any proposed government agency. This argument was part of O'Connor's longstanding belief in free-market medicine including the organization of research and philanthropy. During the war he told one Texas donor that "a system which would compel members of the medical profession to accept without question the scientific claims of anyone would be the same system which would have prevented Sister Kenny from having in this country that full, free and fortunate opportunity, not afforded her by other lands, to present, expound and establish her method. Such a system we now call "the Hitler System." After the war the danger was also Soviet totalitarianism.

Still, the National Foundation clearly benefited from and indeed exploited the American public's fear of polio compared to other more pervasive and significant health problems. In 1947, when medical historian Richard Shryock wrote a brief history of medical research in America, under the auspices of the New York Academy of Medicine's Committee on Medicine and the Changing Order, he made almost no reference to the National Foundation, a striking omission. But in a footnote he did compare the amount of money spent on research of serious health problems such as heart disease (17 cents per death) to polio research ("over five hundred dollars, on poliomyelitis alone!") to show that "standard research expenditures

are seriously unbalanced." When Kenny characterized the National Foundation as a powerful representative of organized medicine, it was not a great exaggeration.

Over the course of the National Foundation's decade of operation it had come to play a significant if somewhat hidden role in shaping American medical politics. Although the organization had been led since its founding by Basil O'Connor, Franklin Roosevelt's former law partner, it had grown away from its early Democratic affiliations and closer to the Republican Party, political leanings shared by many, perhaps most American physicians in the 1940s and 1950s. With the death of Roosevelt in April 1945 the link between the presidency and polio was decisively broken.

The Truman Administration brought health care and medical research to political central stage. When Roosevelt was in the White House Congressmen Robert Wagner of New York, James Murray of Montana and John Dingell of Michigan had introduced national health insurance legislation, and in November 1945, in the midst of labor unrest, President Truman announced his support of this reform. The idea that the U.S. should adopt a national health system, like Britain's National Health Service established in 1946, was exhilarating and disturbing. Most Congressional witnesses saw the policy debates on medical research in the 1940s as part of a broader program by the Truman administration to centralize and restructure American health care. Throughout the 1940s O'Connor maintained close relations with the AMA, the most public critic of

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"socialized medicine," especially Morris Fishbein, **considered** "the voice of the AMA." O'Connor moved the professional weight of the National Foundation behind some of more conservative forces in medicine, such as the pro-vivisection National Society for Medical Research and Fishbein's personal and professional campaign against government health insurance. In February 1948 a National Foundation official wrote to Fishbein, reminding him that he had promised an JAMA editorial "from the standpoint of advocating the omission from the National Science Foundation Bill of any and all special commissions for specific diseases." Fishbein promised in his reply that there would be an editorial in April, and there was.

But by the late 1940s Fishbein's influence in the AMA had begun to decline. His fierce rejection of any kind of pre-paid group practice (even organized by physicians themselves) had alienated many doctors trying to give the public alternatives to the attractive health insurance proposals being offered in Congress and by governors like California's Earl Warren. A major public humiliation occurred in 1943 when the AMA (represented by Fishbein and a local AMA society in D.C.) lost an anti-trust suit brought by the Justice Department that reached the Supreme Court. In 1947 the Justice Department began another anti-trust investigation of the AMA's efforts to restrict group practice. Fishbein was attacked on the floor of the AMA's House of Delegates by California delegates already resentful at his unrelenting opposition to affilia-

tion with osteopaths, and in 1949 Fishbein was deposed as general secretary and JAMA editor, and his public relations work for the AMA taken over by a professional advertising firm. Historian John Burnham has pointed to these events as the beginning of the end of organized medicine's Golden Age.

Kenny became part of these complicated medical politics, and benefited from the lowered reputation of the AMA and its allies. Even some Republicans chose to express sympathy for a medical underdog ignored and exploited by a medical trust. Republican Congressman Joseph O'Hara of Minnesota described the battles between Sister Kenny, the Foundation and "some of the doctors" as a "civil war." New Jersey Republican Charles Wolverton, chair of the Congressional committee that held the health insurance and research hearings, pointedly questioned National Foundation officials about their neglect of Kenny's work and their refusal to fund it. And a Missouri Congressman announced that many people saw the National Foundation as "a sort of medical closed shop, run for the benefit of certain doctors and certain politicians." The link between Kenny and federal polio research was reinforced by petitions circulated by the recently founded Citizen's Polio Research League asking Congress "to pass legislation and provide Federal Funds and Control for Extensive Research on Poliomyelitis." In a private phone conversation in December 1948, recorded by a secretary, Hart Van Riper told Edgar J. Huenkens, the current medical director of the Kenny Institute, that he was sure this new League was "Kenny Foundation No. 2" and was the result of

Kenny's resentment at the shifting power relations at the Kenny Institute and Foundation.

Already on the defensive as an unpopular medical trust, the National Foundation had begun organizing a kind of research public relations project: the First International Poliomyelitis Conference to be held July 12-17 1948. This conference inaugurated a series of international polio meetings sponsored by the National Foundation which were subsequently held every three years until 1962, and their proceedings published with the assistance of Morris Fishbein. Making polio research an international issue -- in line with the recently founded World Health Organization -- showed the American public as well as Congress that the National Foundation was beyond parochial national medical politics. Indeed the word "international" was a coded Cold War term indicating American allegiances with other "free" nations. These conferences, epidemiologist John Paul later reflected, "set both the stage and the American standard for a global type of representation that had not existed before, and was especially welcome in the immediate post-World War II period." But, he recalled, they were "conducted in a lavish manner, and it was obvious that they could not have been put on without the unique financial backing of the NFIP." This "spectacle of medical science being closely allied to fund-raising and fund-spending techniques," Paul believed, caused "the raising of eyebrows" among both American and European scientists.

Kenny of course was not invited to the 1948 conference. Indeed, by this time Kenny was struggling not

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just for legitimacy (on her own terms) but also for her legacy. For a few years after her arrival in the U.S. the Kenny method was widely used and its originator recognized, but, even as medical texts and public health bulletins on polio rejected immobilization and long-term splinting for hot packs and muscle training, they often left out Kenny herself. As early as 1942, when the National Foundation's first medical director Don Gudakunst proposed an exhibit of her work at the annual AMA meeting, officials invited not Kenny but two of her technicians to demonstrate the new therapy. Miland Knapp warned Gudakunst that "Sister Kenny was grossly insulted by being excluded," but Gudakunst told him that "the Foundation is exhibiting Miss Kenny's method and not Miss Kenny." By 1948 there was greater urgency to Kenny's efforts to gain official recognition of her work and her contribution to medicine. Kenny's method was no longer the "latest" discovery in polio therapy. Nicholas S. Ransohoff, an orthopedic specialist based at Monmouth Memorial Hospital in Long Branch, New Jersey, had been treating polio patients with curare, and was gaining media attention. Further, Kenny was publicly challenged by the prominent Cincinnati virologist Albert Sabin, who, in June 1948 told the Akron, Ohio medical society that "the Kenny treatment is a waste of energy, effort and money. It fills the hospitals with extra nurses and creates an unnecessary bedlam there." The money, said Sabin, "could be better used for rehabilitation of the few crippled by the disease, and

for further research."

The exclusion from the upcoming conference denied Kenny an opportunity to demonstrate her work in front of an international audience. Appearing at the 1948 hearings wearing a typically flamboyant plumed hat, corsage and brooch Kenny made her exclusion a central issue. Kenny and her supporters urged Congress to force the National Foundation to invite her as a scientific participant, pointing out that "your departments and the Department of State are sponsoring this Conference." Using Cold War language, the director of the Kenny Foundation told the Committee that the Kenny Foundation "would be most happy to assist in every possible way to establish the fact that the United States is most anxious to cooperate in every possible way to help the world health program."

Hart Van Riper, the National Foundation's medical director, recognized he had to defend what he called "Miss Kenny's charges of being discriminated against with regard to the First International Poliomyelitis Conference." (The National Foundation had for some years a policy of referring to Kenny as "Miss" rather than Sister). Van Riper explained the exclusion by arguing that Kenny's unscientific attitude to evidence made her an inappropriate participant. The conference, he explained, was "open to all qualified medical personnel" and was intended "to pool the knowledge in various countries, since usual channels of communication through scientific journals, etc., were interrupted for a long period during the war." When Marvin Kline, the executive director of the Kenny Institute, had asked to be placed on the program, the request had been con-

sidered by the conference's Advisory Committee chaired by Irvin Abell, president of the American College of Surgeons, and including as members Morris Fishbein and virologist Thomas Rivers. This committee asked for a written plan, and also told Kline that all exhibits were confined to Foundation grantees; "anyone familiar with the procedure of a medical or scientific conference will recognize that this is the only proper handling of such requests," added Van Riper. Kline's proposal was rejected for "individuals who have been selected to compose these panels are capable of answering all pertinent questions with regard to the treatment of poliomyelitis on the basis of established knowledge."

"The Committee is not asking for a restatement of Sister Kenny's contribution to the field of poliomyelitis," Stanley Henwood, the executive secretary of the conference, wrote to Kline, "but rather for some concrete scientific evidence and not merely statements that are based on personal opinion." The Committee required "actual scientific evidence" in "manuscript form" such as "the presentation of a sufficient number of case reports covering all of the patients treated with the end results as compared with cases in the same area treated by other methods."

Throughout her career Kenny did fail to recognize the different weighting of various kinds of evidence. While ostensibly seeking scientific confirmation of her work through clinical investigation and laboratory studies, Kenny relied mainly on evidence from the testimony of others who saw her results, which she described as "reports of unbiased medical men and the findings of science." Such

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testimonials had been commonly used to convince the public of the worth of a new medical technique or a patent medicine in Kenny's youth. Thus, she wrote in frustration to a supporter in 1943, "the poor presentation made to the public by the lay press would dwindle into insignificance if I made a leaflet of the signed statements of medical men of unquestionable ability and many of international repute and distributed this leaflet." Further, Kenny began to appear more intent on shoring up past glory than reforming present practice. As Hart Van Riper pointed out to the 1948 Committee, "in her mind the points at issue are who discovered the treatment, not the value of the treatment; who in her current opinion is qualified to teach it, not how it is being taught today."

After the Hearings

Kenny's appearance at the hearings did not gain her access to the International Conference as a scientific participant. But she was issued a press card by the American Newspaper Guild, and attended as a reporter for the North American Newspaper Alliance. Relegated to the role of a member of the press, dependent on participants on the floor to raise her questions, she was largely ignored. National Foundation publicist Roland Berg reflected to the chairman of a local chapter, Kenny had taken part in at least three general press conferences, "at which were also attending the nation's leading science writers and medical reporters. During those conferences, Miss Kenny attempted to voice her pseudo-scientific facts to the press,

but the press was not at all impressed and reported nothing of her claims." "I fail to see that the National Foundation is in controversy with Miss Kenny, except as it exists in her own mind," Berg concluded his letter." At a meeting of the Citizens' Polio Research League at the recently opened Kenny clinic in the Jersey City Medical Center, according to one report, Kenny complained that she was "thwarted and frustrated while at the conference... Unable to answer questions, given no recognition, and had to sit with press representatives." Foreign delegates, she told the meeting, "were disappointed at the treatment given her at the conference."

In 1949 Kenny formally retired as head of both the Foundation and the Institute. After her dethroning, like Morris Fishbein -- and I find uncanny similarities in their personalities -- she became a lobbyist and consultant, traveling between Australia and the U.S in the final three years of her life, despite battling Parkinson's disease. In 1950 she was a guest on the television show "Meet the Press," as a kind of polio expert emeritus. After Kenny's death in 1952, representatives of the Kenny Foundation, especially medical director Paul Ellwood, continued to appear before Congress during hearings on what was now termed rehabilitation medicine. But Kenny herself, just as she had feared, faded from medical and popular memory.

Elizabeth Kenny did not go to Washington as a maverick nurse with a crazy idea. She was invited to speak as a polio expert, as a kind of scientific discoverer, and as the director of a philanthropy and a polio institute. Nor did her advice about the structure of federal research policy diverge from a

broader, populist suspicion of medical elitism. A number of Congressmen and members of the public shared her sense that lay people and non-elite health professionals should play a role directing medical policy (including scientific research) to ensure fairness and objectivity. With practiced poise and fluency Kenny described the anger she felt, on behalf of the American people, at the ways organized medicine had neglected and (at the same time) appropriated her work. Her testimony did not sway the organizers of the First International Poliomyelitis Conference. But it certainly enhanced her celebrity status. "In all my experience on this committee," chairman Charles Wolverton told Kenny on the second day of the 1948 hearings, "you have had more photographers interested in taking your picture than any witness we have ever had before the committee." "I am afraid I do not make a very pretty one," Kenny replied, with unconvincing modesty. A few months after the conference Gallup pollsters asked the American public: "What woman, living today in our part of the world, that you have heard or read about do you admire most?" The top three women listed were: first Eleanor Roosevelt, then Madame Chiang Kai-shek, and third Sister Kenny.



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