

POLIO NETWORK NEWS

SPRING 1995 ♦ ♦ VOL. 11, NO. 2



Sixth International Post-Polio and Independent Living Conference
JUNE 1994

Coordinating Post-Polio Treatment: You, Your Primary Physician, and Your Expectations

*You ... Dorothy Woods Smith, RN, PhD,
Associate Professor, University of Southern Maine
School of Nursing, Portland, Maine*

Before addressing the topic of our panel I'd like to briefly address how those of us who are polio survivors, especially people who are attending their first G.I.N.I. conference, can sort through the vast amount of information being presented at this conference in a way that will enable us to become empowered rather than overwhelmed.

I would like to share Dr. Augusta Alba's advice to me when we first met in 1986. The reason to attend the International Post-Polio and Independent Living Conferences is not just to obtain information, which most of us can do through reading, viewing, or listening to the conference proceedings. We come here in person to meet other people who share similar experiences, questions, and interests, and to have fun in the process. This is a my third such conference. Experience has shown me that she was right!

We should apply all our knowledge about living as polio survivors to this conference. That means making choices. It means being clear about what we want to do or learn most, and what we can let go. It means pacing ourselves, taking breaks, paying attention to our body positions, and providing our bodies with nourishment and rest. This will allow us to be fully present when the issues of greatest importance to us are discussed. We can fill those nice gray bags with information of interest to our post-polio support groups, our physicians, and therapists — and be generous in distributing it to them when we get home. And we can take home for ourselves information, ideas, insights, and inspiration.

Now, to our discussion of what we can and should expect of our primary physician. I think all of us would like to have what Gini Laurie, the founder of G.I.N.I., referred to as an "R.D." — a real doctor — available to us at all times, and if not in person, then at the other end of the phone. It would also be nice if that person were an expert in all aspects of post-polio syndrome: a specialist in the areas of neurology, orthopedics, pulmonary function, rehabilitation, and psychology. It

would be even nicer if that physician was also a nurturing, caring human being who treated you as a favorite patient. It would be nearly perfect if the physician was always available within a few hours of being called, and had an easily affordable fee.

Most of us here are adults, and have set aside magical thinking. But we can still dream. And it is reasonable to look for a network of health professionals and friends who can collectively provide some of the expertise, guidance, and therapy that we need.

As a polio survivor and a nurse, I want a primary physician who cares enough to listen to me, and who treats me as a believable, reasonable, intelligent human being. This physician does not have to be an expert but does need to know people who are, and be able to arrange for me to see them when it is appropriate. This person needs to be someone I can share information with when I return from the conference, and who will read and/or save the information that I bring.

The person whom I have chosen for my primary physician is an internist whom I see about once a year for an overall check-up. The primary physician has "the big picture" and serves as coordinator of all my health-related needs. I am referred to a neurologist for polio-related symptoms; we have been learning together about my post-polio sequelae for seven years. This year I was also referred to a physiatrist, a rehabilitation specialist new to our area. Reports from the specialist go to my primary physician, and they occasionally consult with one another by phone.

After the physicians diagnose the underlying cause of the symptoms and recommend treatment, they make referrals to the other health care professionals who will carry out the treatment plan. In my case this year I was sent to a physical therapist for treatments to relieve tightness, to a nurse practitioner for strategies for dealing with chronic pain, and to an occupational therapist who devised a program of gentle stretching and energy conservation.

In closing my remarks, I want to add that I believe that we as patients share responsibility for the patient-

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physician relationship. We owe it to ourselves and to them to be direct and honest, to ask questions about what we do not understand, and give timely feedback about our responses to medications and treatments they prescribe.

Your Primary Physician...

**Marny Eulberg, MD, Mercy Medical Center,
Denver, Colorado**

I have a dual role of being a polio survivor and a primary care physician.

As I have gone through life, I have realized that part of the reason I went to medical school was because of some treatments I received as a child and as someone who had polio. I want to say, first of all, that I had very appropriate medical care. But I felt like a lot of things were done TO me instead of for me and without my permission. And as I have gone through therapy and learned more about myself, I realize that one of the reasons I went to medical school was never again would that happen to me. I wanted to have the knowledge, the recognition, and perhaps the peership, so that I could be an active partner in my own health care.

I do not necessarily advocate that all of you go to medical school, or complete a residency. It is a significant price to pay, and I think there are other ways you can be a partner in your health care these days.

Times of medical care have changed. Patients can, and a number of patients do, interview doctors. You are hiring a physician just as you hire other people to work for you. What you are seeking from a health care provider is a determination of what is wrong if you do not know, or some reassurance after your annual physical that a lot of things are very right. You also seek advice about what can be done to take care of problems, or to keep you healthy. And, you seek assistance to perform certain technical procedures that you cannot do yourself.

The whole process of hiring a physician should not be unlike that of hiring an accountant, a lawyer, or a mechanic. And it is fraught with some of the same problems. When I take my car in to be fixed, they can tell me a lot of things about alternators and generators and TVC valves and other things I have no idea about. In my relationship with my mechanic, I have to have some trust, and you have to have some trust with medicine.

These days, however, the process of hiring a physician gets a little muddied, or sometimes very muddied, by insurance restrictions, particularly HMO's (Health

Maintenance Organization) that have closed panels of physicians and are very stingy about out-of-plan referrals.

It appears to me that sometime within the next few years we are going to have some kind of national health insurance here in the United States. It also appears that it will be an HMO model. If it becomes a reality, all of you here in the United States are sooner or later going to have your care coordinated by a primary care physician. (Some of you may already be in that situation.) If you have enjoyed the option of calling and making an appointment with any specialist in the past those days may be limited. In the future, you may need to develop a relationship with a primary care physician.

Primary care physicians, by most HMO's, are defined as either a family physician, general internal medicine physician, a pediatrician, and in some cases an obstetrician-gynecologist for women's health care.

There are differences among the physicians and their training. Family physicians have, in general, a little broader training because they take care of children, adults, sometimes pregnant women, and generally have had some training in some minor surgery. It is said that they can handle 90% or 95% of the problems that come in their office.

Internal medicine physicians mostly have had training with diseases of adults, generally have had less gynecology training, and less surgical experience. They may not be able to take care of quite as many things in the office.

As you all know, not all primary care physicians know about polio or post-polio. Some are willing to learn and some are not.

I have heard from many polio survivors in the past of the frustrations with physicians, but I never experienced it until last summer. I gave a 20-minute talk at a musculoskeletal conference for primary care physicians in Breckenridge, Colorado, and when the comments came back from the audience at least half of the comments were, "I don't know why you put polio on the program; I am never going to see polio. It was a total waste of my time." These represent the physicians who are not willing to listen and learn.

As a primary care physician, I know that primary care physicians cannot know it all. At least 50 different high blood pressure medicines, about 100 different antibiotics, and 40 different birth control pills are now available. I know most of the names, generally what they are for, and a couple of the side effects, but I cannot even come close to knowing all of the details. And that is true in a lot of other areas of medicine.

Please value a physician who says, "I do not know" and who, in front of you, gets out the books and looks it up or gets on the phone and asks someone else. A physician who knows it all is lying.

Primary care physicians, as well as all physicians, have good and bad days just like you. There are also physicians you will work well with and others with whom you will not. And some of the physicians with whom you do not work well will be deemed great by others.

It is possible that a physician may have just entered the office after having had a terrible fight with a teenaged son, or may have just told the patient before you that they have a terminal disease. There will be days that your physician is struggling to keep things together and may not be there for you. If this happens all the time, start wondering. If it is unusual, your physician may be showing some of his/her human side.

Physicians also sometimes make mistakes. One of my professors in medical school told us that we should not be in medicine unless we could live with the fact that some day we would kill a patient because of something we did or we did not do. So far I do not think I have had to live with that, but it is reality.

Most physicians will not make mistakes intentionally or maliciously, although there are physicians who have problems themselves, such as drugs. As a profession, we need to weed them out.

Most primary care physicians schedule a patient every 10 to 20 minutes. If you have many issues to deal with and lots of questions schedule more time. Do not expect that they can spend an hour going over your problems. If they do, the other scheduled patients in the waiting room are getting very angry.

Try not to save your most important issues for the end. Try not to talk about the sunspots on your skin that bother you along with the fact that you do not like it that you are balding, and then at the very end, mention that you are very depressed and have considered suicide. The "oh, by the way" at the end are difficult for most physicians because we realize their importance. It has bothered you a lot which is why you had a hard time bringing it up and saved it to the end. When it is an "oh, by the way" and I know I am a half hour behind, you may not get the appropriate evaluation and care that you need immediately. I may do a quick short and sweet evaluation that could miss some important things.

Also understand that most physicians have "work-in" appointments for emergencies. If you call with a temperature of 104, you need to be seen that day. Those appointments are for emergencies or single acute problems. It is not the time for you to bring up 10 or 12 concerns and complaints. Physicians cannot do all of those problems justice in a "work-in" appointment.

If you have special problems, like difficulty getting on or off the exam table, it is useful to tell the office in advance. Most primary care physicians, or a number of them, do have a procedure room with a table that will go up and down. They usually only have one and it is

just more efficient for everybody if the staff knows ahead of time.

If you are coming for a problem, do not also bring along other sick family members. Do not expect indirect or direct assistance by saying, "Oh, by the way, my granddaughter has a sore throat. Could you just take care of that while I am here?"

Write down your questions and concerns. It is also helpful for you to bring a list of your medicines and dosages. Telling me that you are taking a little pill for your heart is not very helpful. I used to know the high blood pressure medicines by color. But with the number of generics, and the fact that they do not have any identifying marks on them, I cannot look them up and find out what they are. Bring in your medicines; bring in the facts.

It is also useful for you if you have had a number of orthopedic surgeries, when you are seeing the physician for the first time, to bring a list of the surgeries and the approximate dates.

And lastly, it is helpful when you call a physician, to give the office an idea of how urgent the problem is. If I have a list of 10 phone calls, and I have no idea how to prioritize, I start at the top of the list and go down. Usually the first call in the morning is at the bottom of the pile. If you are having chest or abdominal pain, you should tell the office staff that it is urgent, and then I know whom to call first.

Additionally then, be available for a return call or specify with the original message when you are available. I

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INTERNATIONAL POLIO NETWORK

5100 Oakland Avenue, #206
St. Louis, MO 63110-1406 U.S.A.
314/534-0475
314/534-5070 Fax

ISSN 1066-5331

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

ISSUED QUARTERLY

EDITOR/EXECUTIVE DIRECTOR ♦ Joan L. Headley

PUBLISHER ♦ Gazette International Networking Institute (G.I.N.I.),
5100 Oakland Ave., #206, St. Louis, MO 63110-1406 U.S.A.,
314/534-0475

New Fees Effective July 1995

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am fairly patient and will keep trying up to nine, ten times. A number of physicians will only give people one or two tries, and if you have not answered they throw the message away and wait for you to call again.

And lastly, if every time I call you I know I am going to be on the phone for 30 minutes, I will not return your call until the end of the day. If I know that I can talk to you in a few minutes, I will call while someone is getting undressed or dressed or after I have seen a well child and sent in the nurse to give the shots. In other words, make sure that you keep phone calls brief if possible.

Your Expectations ...

Stanley K. Yarnell, MD, St. Mary's Medical Center, San Francisco, California

I am not a polio survivor. I have a visual impairment due to recurrent optic neuritis. My expertise regarding relationships between patients and physicians is based on personal and professional experience.

First of all, relationships between physicians (all health care professionals) and patients have evolved as medicine has evolved. Polio survivors have been part of that change. Originally there was the apostolic model in which the physician was the healing priest. Information was handed down from on high. The relationship has evolved to a more collaborative model with the health care professionals and the patient working together.

A good collaborative physician-patient relationship — and that includes the primary care physician, specialist, and the patient — is truly a team effort and fundamental concepts of effective team building are applicable.

Any really productive relationship requires effective communication, and, above all, listening. As a patient, sitting across from a health professional, listening is very important. You should be able to repeat what your physician has to say. If you can not repeat it, you have not understood it. From my perspective as a physician I know listening is important and that if I listen hard enough the patient will tell me the diagnosis. I just have to take credit for it and bill!

Sharing information among a team such as the primary care physician and the specialists (neurologist, physiatrist, orthopedic surgeon) is an important part of communication. Frequently, it falls disproportionately on the shoulders of patients. Physicians need to work at communicating. With managed care expanding, we will all be compelled to communicate more effectively.

As health care professionals giving out information, we need to minimize the jargon. We learn jargon to feel important, but the major benefit is the way it streamlines speech.

For patients, it is important to get to the point and be succinct. Many of my patients write things down ahead of time so they do not forget their questions or all of the points they need to make. Remember, as a physician, I can get the diagnosis from you by listening.

As I talk to polio support groups, I repeatedly hear, "My physician's an idiot. He doesn't understand. He doesn't listen." And many physicians have said, "They just go on and on. They come in and expect me, in 45 minutes, to be able to solve all of their problems which they have not taken care of for the last 30 years."

Everyone is angry, and I think we need to be aware of it. It is easier to talk about than it is to solve. But one thing we can all do, whether we are sitting on the physician's side or the patient's side, is not to let things brew and stew and turn into anger. If there is conflict it should be dealt with. If you feel that you do not want to, or cannot deal with it face to face, or have not figured it out during your appointment, write a letter or telephone. And if you cannot talk directly to your physician, or the physician has some issue, it is important to communicate somehow whether it is with the dreaded phone mail technology or with someone else in the office. Issues of conflict need to be resolved so the therapeutic relationship does not get bogged down.

It is important that this collaborative team share goals and expectations. My perspective and expectation as a physician of what I can do for polio survivors in a clinical situation is to help them feel healthy and as functionally independent as possible — doing those things they want to do. Some polio survivors who come to me may have a completely different expectation. They may be searching for a cure to get rid of this new disability, so they can do the same old things they have always been doing. These are two completely disparate goals. Unless there is a shared goal — a mutually-agreed-upon expectation — there will be conflict.

It is absolutely crucial to have honesty and trust and that takes work and is a two-way street. You expect your physician to be straightforward and honest and not hold back anything about your prognosis. At the same time, your physician expects you to be completely honest and to share, for example, if you are seeing a post-polio specialist or admit that you are taking certain medications.

And finally, we all need to acknowledge and compliment each other's positive qualities. I am probably most effective in relationships where patients give me some strokes as well. □



The Battle with Bracing

John R. Fisk, MD, Southern Illinois University School of Medicine, Springfield, Illinois

Dr. Fisk's introduction to polio came in the early 1970s when he was a U.S. Army orthopedic surgeon in Korea for two years and saw acute polio firsthand. He travels annually to Central and South America to work with children with polio.

In post-polio survivors the incidence of scoliosis has been estimated at 30%, a rather large number. Factors contributing to scoliosis are the severity of the weakness at the time of the acute illness and the region of the spine affected (the curve location may be dependent on those muscles that are weak). However, there are individuals who have significant spinal deformities with very little demonstrable trunk weakness — only lower extremity problems. The factor important, in this instance, is the age at which the paralysis occurred. The younger the age, the longer the growing period of the individuals and, consequently, the greater the likelihood the progression of curvature.

In post-polio survivors, the iliotibial band, that thick bank of tissue that goes from the side of the pelvis down to the knee, frequently becomes tightened and contracted and can cause the pelvis to tilt. Once a spine is out of balance in a growing individual, scoliosis can progress and develop.

There are different curve types. The classic, paralytic curve not only typical of polio, but also of cerebral palsy, muscular dystrophy, and some of the other spinal cord lesions, is the long C curve. Other curve patterns may also be present in these cases.

A frequently problematic curve is the lumbar curve — the lower curve that causes obliquity (not level) of the pelvis. Pelvic obliquity can impact the level of function. Someone with a pelvis at a 45 degree angle who is a full-time sitter, in reality sits all day on one cheek. It is a significant problem, not only with sleepiness in the skin, but with pressure sores and actual discomfort.

School screening done now for most of our children is a major priority of the Scoliosis Research Society. It began in 1962 in Delaware and Minnesota looking for residual deformities of polio. They soon found that scoliosis was not only due to polio but due to other causes, primarily idiopathic (cause unknown) scoliosis.

In 1956, Jip James, MD, felt that the curve was due to a weak side. If muscles are imbalanced, the spine is going to become crooked. Considered an oversimplification, we now know one of the underlying causes of idiopathic scoliosis may be very subtle spinal cord abnormalities and abnormalities in the balancing mechanism.

How are these deformities treated today?

What about bracing? A modern Milwaukee brace is much different than the old one. Bracing by a new Milwaukee is only effective in individuals who are not yet through growing. Bracing of spinal deformities in a skeletally mature individual as an adult is of real questionable benefit. Certainly, one cannot straighten the spine or prevent it from progressing. However, one may be able to slow that process of progression.

Frequently braces simply cover up what is underneath. To illustrate, consider an African lady who wore copper rings around her neck as a ritual of beauty. Women wore this adornment unless they were adulterous, in which case it was taken off.

Frequently, the neck was so weak the head fell over and the individual died. *National Geographic* found a lady who had her rings taken off and compared her x-ray with a normal x-ray. They showed that the neck did not change at all. It was only a deformity of the ribs that occurred to give it the appearance of an elongated neck. The point being — this is what braces may do.

Braces have to push on something and when the curve is too severe, they will push on the ribs and deform the ribs much more than they will control the curve. For treatment in growing individuals, we observe curves from zero to 20 degrees, we brace curves between 20 and 40 degrees, and we operate on curves over 40 degrees. The effectiveness of the brace has been better defined within the last 10 to 15 years to be for a very small range of severity, such as curves with proven progression with the above defined limits in an individual with at least two years of remaining growth.

Treatment is quite different, however, in the adult. Traction has been proposed, but is fraught with complications such as osteoporosis and the loss of mineral con-



A modern Milwaukee brace

tent from immobilization. These, as well as phlebitis, may result from the prolonged bed rest necessary for the traction.

The development of the halo allows us to apply traction in a sitting position, or even in a walking position, and thus prevent osteoporosis, facilitate pulmonary function, and allow a period of time of convalescence for individuals with severe pulmonary problems.

In a series of patients from Minnesota, halo traction was offered to 20 patients with severe deformities between 90 and 200 degrees. Fifteen had severe pulmonary function with a lung capacity in the range of 25% of normal. Whereas 15 of the 20 opted to try the halo traction, only nine of them were able to go on for surgery. In the nine who were able to tolerate the process, the blood arterial oxygen went from 55 mmHg to 64mmHg. After surgery, the CO₂ came down from 52mmHg to 43mmHg. Vital capacity almost doubled by improving the chest wall deformity. (mmHg — millimeters of mercury; measurement of pressure of oxygen in blood)

Who should have surgery? It is a question about which all of the experts would disagree. Here are some guidelines. Surgery may be indicated if one has curve progression, has pain, or pulmonary compromise. There are many factors that affect pulmonary function so it is a soft indication.

The last criteria is osteoporosis or the softness of the bones. Good bone structure is needed to anchor hooks and wires and hold the spine straight. (My oldest patient has been 55 years. Some will operate on age 60, but it becomes very individual based on bone stock.)

Surgery is much safer than it used to be and every year is getting more safe. A cell saver that will recapture blood after surgery, cleanse it, and return it to the patient is now used, significantly diminishing the need for blood transfusion. Spinal cord monitors are also used during the surgery to help insure that the spinal cord is not injured.

A representative patient. A 45-year-old post-polio gentleman had a curve measuring 90 degrees inside his corset. He knew he had a spinal curvature, but felt quite erect. Without the corset, he could not sit for more than 30 minutes without getting back pain. His pelvis was at 45 degrees. Not knowing whether he was stable, having minimal symptoms, or whether he was progressing and having difficulties, we followed him. A year later he had progressed 18 degrees. We proceeded with pulmonary function studies and other appropriate tests and operated giving him a level pelvis. He will be the first to tell you that it was not easy. He was advised he would be out of work for six months. And indeed he was. He is now a year following surgery and quite comfortable. His vital capacity went from 61% to 73% of normal. His ability to

cough and create a good expiratory effort went from 57% to 79% of normal. He no longer wears a corset and, most importantly, his energy and stamina are greatly improved.

Accurate diagnosis is important. In the case of scoliosis, there are other things besides post-polio syndrome, and frequently it is simply degenerative changes in adulthood. The number one thing the medical profession can provide is education and understanding. Then patients can make the decisions for the proper approach to treatment.

Rest with judicious exercise, and in the case of extremity involvement, new orthotics are offering a great deal to post-polio survivors. However, in the spinal deformity area, I am cautious about recommending braces.

There is treatment available. The approach is one of appropriate evaluation, not simply rushing because something must be done. □

RESOURCES: The Scoliosis Association, P.O. Box 811705, Boca Raton, FL 33481-1705 (407/994-4435); Scoliosis Research Society, 6300 N. River Rd., Suite 717, Rosemont, IL 60018; The National Scoliosis Foundation, 72 Mount Auburn St., Watertown, MA 02172 (617/926-0397).

The presentation of Glenn Ham-Rosebrock, CO, during the session The Battle with Bracing, will be featured in the next issue of Polio Network News, Vol. 11, No. 3.

New Insights into ALS and the Impact on Post-Polio Research

**Raymond P. Roos, MD, Co-Director,
Post-Polio Clinic, University of Chicago
Medical Center, Chicago, Illinois**

For over 10 years I have been the Director of a NIH-funded Program Project entitled "Motor Neuron Diseases," which focuses on amyotrophic lateral sclerosis (ALS; Lou Gehrig's disease) and post-polio syndrome. One of the premises of this grant is that the mechanisms by which motor nerve cells die may be shared by varied diseases, i.e., we may learn more about post-polio syndrome by learning more about ALS and vice versa. In this article I will discuss new knowledge about ALS and how it may impact on our understanding of post-polio syndrome.

When I took over as Director for the Program Project, I thought it most valuable to try to take advantage of the new powerful technologies in use in genetics in order to learn more about how motor neurons die. For this

reason, I invited Dr. Teepu Siddique and colleagues (then at Duke University) to submit a research project in this Program Project in order to identify a "link" between susceptibility to familial ALS (FALS) and inheritance of a particular chromosome from an affected relative. As a result of his studies and many other collaborations, linkage was discovered and, about a year ago, the gene responsible for FALS was identified as superoxide dismutase-1 (SOD).

What does SOD do? SOD breaks down free radicals which are toxic products of cell metabolism. Free radicals have been implicated as a cause for cell death for years. The realization that mutations in SOD-1 lead to motor nerve cell death provided the first clear-cut evidence that free radicals could play a role in motor neuron degeneration. The actual mechanism by which motor nerve cells are specifically targeted is presently under intense investigation.

What are the implications of the discovery of SOD mutations in patients with FALS? Only 5-10% of cases of ALS are familial and only 20% of FALS cases are caused by SOD-1 mutations. Nevertheless, there is a strong feeling in the scientific community that the mechanisms of motor nerve death in sporadic ALS as well as other neurodegenerations may be similar to that in FALS. This same mechanism may also be responsible for the motor nerve cell death seen in post-polio progressive muscular atrophy.

What future directions are being pursued? One direction of great interest is the development of drugs that can counteract the effect of the mutant SOD. A great resource for the scientific community is the availability of experimental mice that carry the mutant human SOD gene and also develop an ALS-like syndrome. These mice are critically important in the development of new experimental treatments that can prevent the motor neuron degeneration. When new effective drugs are identified, they may be of use in post-polio patients as well.

These breakthroughs in ALS research are undoubtedly the most exciting ones that have occurred since this disease was first discovered over 100 years ago; I am optimistic that the new discoveries will also help us to understand a variety of neurodegenerative processes. These new insights are a testament to the powerful DNA recombinant technologies that are now available to investigate neurological diseases that have eluded our understanding. We hope that these new tools will also help clarify some of the mysteries of the post-polio syndrome and lead to their effective treatment. □

Reprinted from *40th Anniversary Celebration Salk Polio Vaccine*, the program book for the April 12, 1995 commemoration.

Survivors

Frederick M. Maynard, MD, MetroHealth Medical Center, Case Western Reserve University School of Medicine

As the 40th anniversary of the Salk Vaccine's success is commemorated, it is also appropriate to acknowledge the pioneering contributions that survivors of paralytic polio have made to late twentieth-century medicine and society. Polio survivors have demonstrated the power of the human spirit to rise above adversity from physical disability and they have made many important contributions.

They were guinea pigs for medical experimentation with artificial life-support systems and with orthopedic surgery procedures to restore lost function of limbs. They and their families first demonstrated that home care for people with the most complex of medical needs is not only feasible, but creates opportunity for high quality of life.

Polio survivors have led the battle to change society's attitude toward people with all types of disability — from the first 'mainstreaming' school programs to the recent Americans with Disabilities Act. Even today, they are still pioneers as they become the first large group of people with severe physical disability to grow old while living active and productive lives in their communities.

Medical rehabilitation professionals are applying the lessons learned from their life experiences to many current types of disabling conditions, such as traumatic spinal cord injury and brain injury. Polio survivors also remind us to remain concerned for the welfare of millions of polio survivors from the Third World who did not have the benefit of vaccination during the past 40 years and to renew our efforts at eradicating the last remaining pockets of endemic polio from Africa and Asia. As we remember the miracle of successful polio vaccination and honor its pioneering developers, let us also give thanks for the miracle of the other polio pioneers — the survivors! □

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Input from Polio Survivors Wanted

Nancy Seyden, Co-Director, Research and Training Center on Neuromuscular Diseases, University of California, Davis

Not generally well known, neuromuscular diseases include some forty different disorders and affect over a million people in the United States. Neuromuscular disease can affect the anterior horn cells in the spinal cord (as in polio and post-polio), the peripheral (motor) nerves (as in Charcot Marie Tooth), the myoneural junctions (as in myasthenia gravis), and the muscles (as in muscular dystrophy).

Common effects of neuromuscular diseases include weakness, fatigue, atrophy of the skeletal muscles, limb contractures, spinal deformity (such as scoliosis), restrictive lung disease, cardiac dysfunction, and cognitive defects. All can decrease quality of life, educational opportunities, employment opportunities, and increase dependency and disadvantage.

The Research & Training Center (RTC) on Neuromuscular Diseases at the University of California, Davis, has been funded for the past ten years by The National Institute on Disability and Rehabilitation Research (NIDRR). It was recently refunded for another five years. One of forty-eight RTCs in the United States, all mandated to provide specific programs of research and training on

aspects of disability and rehabilitation, ours is the only one studying neuromuscular disease rehabilitation.

Research projects include studies on physical performance and nutritional status; evaluation and treatment of swallowing disorders; dyspnea (difficulty breathing), respiratory control and therapeutics; employment opportunities and vocational rehabilitation; educational mainstreaming of children and young adults; and strategies to improve quality of life and community integration.

The RTC Quality of Life project is looking at ways to improve quality of life, and to improve access to information and services for disability issues.

The Quality of Life Project is currently working on:

- ◆ A survey to identify financial, social, and functional difficulties faced by people with disabilities, in order to improve services.
- ◆ A resource manual that provides answers and tips to commonly asked questions by people with disabilities.
- ◆ Access to computer bulletin boards for information about disability issues.
- ◆ Identifying major transitions, barriers, and service needs of individuals who have long-term experience with disability.

The project is designed specifically to encourage input from consumers with disabilities, their families, and service providers in order to help identify unmet needs and barriers. We are facilitating support groups, focus groups, consultations with experts on disability, interviews, and surveys of persons with neuromuscular disabilities.

We need the participation of individuals who had polio to help us document and address these issues. A survey which includes questions to determine information needs, service needs, health care, insurance, control of one's life, acceptance of disability, and level of physical functioning has been designed and takes approximately one hour to complete. By University regulations, all information including names and addresses will be confidential. The survey targets young adults who are sixteen and above, and adults.

To become a potential participant in this research, fill out and return the form on the facing page of this issue of *Polio Network News*. Upon receipt we will send you the information requested, an informed consent by you to participate, and a survey.

If you would need an alternate format, please call (916) 752-5882, and ask for Nancy Seyden.

To be a participant, forms must be received in one month. ☐

Readers Write

UPDATE: Lois in California heard from several individuals and now has functioning Kenny sticks. ◆ B. Ruth Brock Brewer from Missouri found her childhood friend, Elizabeth Hornsey Reeves from the polio support group at Northwestern in the Chicago area. Elizabeth is leader of an offshoot called Time Travelers. Writers with disabilities meet once a month creating and critiquing manuscripts. For more information about Time Travelers, contact Elizabeth Reeves, 215 E. Chestnut, #1601, Chicago, IL 60611. ◆ The address and phone for Toe Heaters is 4600 Danvers SE, Grand Rapids, MI 49512 (616/940-1914).

NEW REQUESTS LOOKING FOR

- ... Hope Woolley and Jennifer Willard
- ... information about Lown-Ganong-Levine Syndrome
- ... anyone with polio and iritis
- ... suggestions for funding for equipment
- ... civil servants who have successfully obtained disability based on the late effects of polio
- ... suggestions from individuals with the late effects of polio on how adaptations have been made in the work place
- ... a 3 1/2A Monaghan chestshell
- ... copies of *Polio Network News*, Vol. 1, No. 2, and Vol. 1, No. 3

NIDRR RESEARCH & TRAINING CENTER

Rehabilitation in Neuromuscular Diseases
Dept. of Physical Medicine & Rehabilitation
University of California
Davis, CA 95616-8655

TDD/FAX: (916) 752-3468
Phone: (916) 752-2903

WE NEED YOUR PARTICIPATION TO IMPROVE THE QUALITY OF LIFE OF PERSONS WITH DISABILITIES

Hello! My name is Nancy Seyden. I am a person who has lived with a severe neuromuscular disability for over 30 years. Like many who live with a disability, I am often frustrated when I try to use services specifically set up for people with disabilities. I also frequently get the run around when I try to obtain information about disability-related issues.

After thirty years, it is still difficult for me to get accurate, up-to-date information that I need to make major decisions, decisions that will affect both my life and my physical survival. I still face major financial and employment disincentives, even though I have worked continuously for the last 18 years.

It is my desire to improve the lives of people with disabilities. That is why I am writing to you today. I am a co-director of a study at a nationally funded Research & Training Center that is looking at ways to improve the quality of life, access to information, and utilization of services for people with disabilities. I came to this research project with three goals in mind:

- To design a project that encourages input from consumers with disabilities;
- To document needs and barriers facing people with disabilities today;
- To make changes that will improve the lives of people with disabilities and their families.

To reach these goals, I need your help. I hope you will participate by agreeing to complete a survey that is designed to study quality of life issues of individuals with neuromuscular disabilities, including post-polio. This information will be used to identify financial, social, and functional difficulties faced by people with disabilities and to improve services to them. I need your participation to help identify the most crucial needs of individuals with disabilities.

I am working through the Gazette International Networking Institute to solicit your participation. You can help me by agreeing to become a potential participant in this research study. Fill out the form below, tape it shut, and drop it in the mail. Upon receipt, I will send a consent to participate form and a survey that takes approximately one hour to complete. All information including names and addresses will be confidential. Thank you for your interest.

Sincerely,



Nancy Seyden

P.S. Our Research and Training Center for the Rehabilitation of Neuromuscular Diseases has also started a computerized bulletin board that gives people information about disabilities. If you are interested in learning how you can use computers to access information, please indicate your interest in the form below.

YES, I will complete a survey for this UC Davis study!

Last Name: _____ First Name: _____

Address: _____

City: _____ State: _____ Zip Code: _____

Telephone number: _____

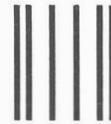
Please list the neuromuscular disease of interest to you:

YES! I am interested in learning about ways to access computerized bulletin boards to obtain information about disability. Please add my name to your mailing list.

Fill out this form and mail it after folding and taping to:
Research and Training Center, Med: PM&R, TB 191, UC Davis, Davis, CA 95616

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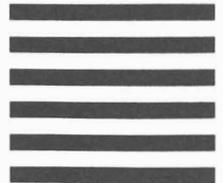
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Haiou Yang, PhD, born and raised in China, and Joanne Y. Yamada, MEd, a third generation Japanese-American who was disabled at birth with cerebral palsy, went to China for a 21 day study-visit. The purpose was twofold: to collect information on persons with polio with emphasis on the concept of aging with a physical disability and to study cultural attitudes about disability and rehabilitation in China. Their trip was funded by the International Exchange of Experts and Information in Rehabilitation (IEEIR) which, unfortunately, lost its funding before their report could be published. *Polio Network News* is pleased to publish its condensed summary. For a full report, contact Joanne Y. Yamada, 1409 Kinau St., No. 3, Honolulu, HI 96814 (808/537-6333).

JOAN L. HEADLEY, EDITOR

Disability, Polio, and the Late Effects in China

"As a person with a disability my standard for marriage cannot be too high. My wife is also a person with polio. Our marriage is probably happier than a normal person's."

"After I reached my teens, my parents often taught me to be independent in doing everything. They tried to nurture my ability to live independently. At the same time, they taught me to have self confidence, to study hard, and to cultivate myself. Polio has had no impact on my relationships with my friends and my neighbors."

"From the day I went to pre-school, to high school, and when taking the university entrance examination, to finding a job, I got unequal treatment and was discriminated against because I was a person with polio." (Before 1990 persons with disabilities were not allowed to attend a university.)

"The inaccessibility and inconvenience of public facilities have caused difficulty that persons with disabilities cannot overcome themselves. I hope that the society can improve accessibility in public facilities and implement a construction law with emphasis on accessibility."

CHANGING AWARENESS AND ATTITUDES

Prior to 1980 persons with disabilities in China were almost invisible and devalued as indicated by the use of the Chinese character "canfei" meaning crippled and useless when describing individuals with disabilities. Deng Xiaoping's son, Deng Pufang, after receiving medical treatment for spinal cord injury in Canada, returned and influenced disability awareness. He coined a new term "canji" for describing persons with disabilities. Canji is translated to mean disability associated with illness.

He established organizations for persons with disabilities and, ultimately, The Disabled People's Federation became an administration at the Ministry level and an entity for consumer advocacy. For example in one county, the Federation assisted its 10,800 citizens with disabilities by providing employment similar to sheltered workshops found in the U.S., and acting as a matchmaker for arranged marriages.

By 1990, the government had passed the Law of the People's Republic of China on the Protection of Peoples with Disabilities which was implemented by a National Five Year Plan for People with Disabilities.

China conducted a national survey on persons with disabilities in 1987. The survey results suggest that there are 1.83 million people with polio. The number of persons with disabilities in China could be 51,640,000, or approximately five percent of the total population. UNICEF considers these numbers to be low compared to other nations. The low number may be due to incomplete statistics and/or a definition of disability that focuses only on the most observable sensory, physical, and mental disabilities.

Based on the 1987 survey, The Disabled People's Federation proposed and implemented Three Campaigns of Rehabilitation: (1) Cataract surgery for persons with visual impairments, (2) Training for children with hearing and/or speech impairment and, (3) Orthopedic surgery for persons with polio.

"I stayed in the hospital for a period of time, but I don't remember how long. Later on, I tried herb medicine, massage, and acupuncture. When I was nine years old I even tried the pressure-point-deep-stimulation method. However, none of those treatments helped."

"My parents did not care how much money they had to spend on treating my illness as long as it could be cured. Because of this I stayed in the hospital for years, since I was one year old. From 1954 to 1958 my hospital fee was as high as 20,000 Yuan." (The average annual salary per capita is 500 Yuan.)

"None of the treatments helped. My parents tried to improve accessibility at home themselves. For example, they changed the door handle, and made a toilet seat, and built a ramp. With a thread of hope for the possibility that I would be cured, my parents have tried their best to help me even in my adulthood. They have always been ridden with guilt."

SURGERY — TREATMENT OF CHOICE

The target number of orthopedic surgeries on persons with polio during the Three Campaigns was 300,000. The actual number of surgeries completed was over 400,000.

Surgery is the popular remedy chosen by parents for children who had contracted polio and is recommended

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Disability, Polio, and the Late Effects in China
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by medical and rehabilitation professionals. Children who had polio are considered a "huge burden" on families. Family members are the primary caregivers so it is necessary to make children as independent as possible. The negative stigma of using assistive aids is also a factor for choosing surgery.

The cost and demand of surgery has inspired new procedures. One noted orthopedic surgeon can complete a tendon-lengthening operation in one minute, and a pelvis lengthening procedure in 15 minutes allowing him to perform eight to ten surgical procedures a day.

Post-surgery care is not available and rehabilitation programs after surgeries are minimal. Many patients who live in the countryside receive no therapy. The only comprehensive rehabilitation center in the country, the China Rehabilitation Research and Training Center, is located in Beijing and was established in 1988. It combines Western practices with traditional Chinese medicine.

There have been only limited studies on the short-term side effects of the orthopedic surgery, and the long-term effects have not been explored.

"For 10 years in Pudong I had to take a ferry from Shanghai City to my factory every Monday. I fell all of the time because of the shaking, upward bridge to the ferry, and the long distance and the muddy, unpaved road. Later I was transferred to work as an accountant in Shanghai so that I did not need to take the ferry. But, my health just got worse."

LATE EFFECTS OF POLIO

Questions about the concept of the late effects of polio elicited a variety of responses from health professionals. Some had never heard of it. Some explained it as being the equivalent to residuals of polio which can be rehabilitated through orthopedic surgery. Surgeons aware of

the concept of post-polio, however, expressed that they were primarily concerned with the younger generation.

A French UNICEF project officer queried, "Is late effects of polio culturally specific to the United States?" Researchers within the Chinese Research Institute for Sequelae of Poliomyelitis were familiar with the concept of the late effects of polio, being introduced to it during a 1988 conference with physicians noting clinical observations of the late effects of polio. Older people with polio who express some of the late effect symptoms are told it is all part of the growing old process.

Acute polio is still a significant public health issue. During the cultural revolution (1960s-1970s) a record fifty to sixty thousand cases were recorded. Expanded efforts by China's Ministry of Public Health to immunize the nation's children has proved beneficial. In 1990, WHO reported 5,095 new cases of polio, however, by 1993 the new cases were at an all time low — 653. Treating older people with polio with new disability is not a priority. Professional attitudes may change, however, as China's goal of eradicating poliomyelitis by the year 2000 is accomplished.



**INTERNATIONAL SYMPOSIUM AND EXHIBITION
ON ORTHOPEDIC AND PARALYSIS SEQUALAE
REHABILITATION, Beijing, China, October 16-20, 1995.**

Contact: Mr. Hejian, China International Conference Center for Science and Technology (CICCST), 44, Kexue Yuan Nan Rd., Shuang Yu Shu, Hai Dian, Beijing 100086, P.R. China.

MOVING??

Please send your old and new addresses to:

International Polio Network
5100 Oakland Ave., #206
St. Louis, MO 63110-1406 U.S.A.