

## Reports from Fifth International Polio & Independent Living Conference

"Bridging the Gap between Research & Clinical Applications" by Frederick Maynard, M.D., "The Body AND the Mind" by Jack Genskow, Ph.D., and "Being an Active Participant in Your Health Care" by Dorothy Woods Smith, R.N., were presented at the Fifth International Polio & Independent Living Conference. Their remarks provided a transition from the research reports (Polio Network News, Vol. 5, Nos. 3 & 4) to the panels discussing "prescriptions" for the late effects of polio which will be printed in future issues of Polio Network News. These articles are followed by a revision of the remarks made by Raymond Roos, M.D., during the research panel. This article is clearer than the original version published in Vol. 5, No. 4.

### THANK YOU

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### Bridging the Gap between Research & Clinical Applications

By Frederick M. Maynard, M.D., University of Michigan, Ann Arbor, MI

We the collective people from around the world who are interested in the late effects of polio have always been the unique aspect of G.I.N.I. (Gazette International Networking Institute) conferences. Attendees include an unusual mixture of professionals working in the field of medicine and rehabilitation and people who are experiencing the problems.

The major theme of the 1981 international G.I.N.I. post-polio conference in Chicago was one of trying to validate a problem. At that point in time, no one really knew whether there was such a thing as late effects of polio. But the survivors knew. They were experiencing many new symptoms, they weren't getting any answers, and professionals didn't understand. So a major part of the first meeting had to be defining the problem.

There have been three subsequent G.I.N.I. conferences. Also two research symposiums held at Warm Springs, Georgia, brought together researchers from around the world to share ideas and the results of studying the late effects of polio.

Once the problem was defined in '81 and '83, we have spent the last three to five years both describing it and determining who has it. Some studies have been population-based, and some have been based on questionnaires and surveys. We've gone through a stage of focusing our research energies to break down the difficult problem of late effects of polio into pieces that can actually be studied.

One of the problems that we face is semantics. We need to reach some common understanding of the terminology we use. The definitions that I would like to propose are these.

### Late Effects of Polio or Polio Sequelae

--specific new health problems which result from chronic polio-caused impairments.

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### Post-Polio Syndrome (PPS)

--the symptom cluster of muscle weakness, fatigue, and pain resulting in new disabilities.

### Post-Polio Progressive Muscular Atrophy (PPMA)

--new weakness and/or atrophy in muscles with clinical or subclinical signs of chronic partial denervation/reinnervation compatible with previous acute polio.

First of all, there are problems that are unrelated to the person's past history of polio. With some new health problems there is no reason to believe a causality or a relationship between the history of polio and the new health problems exists.

Secondly, there are late effects of polio or sequelae of old polio which are probably synonyms. Late effects of polio or polio sequelae refer to any number of conditions that are occurring when there is some causal relationship as well as a time relationship between the new health problem and a history of polio. The new problem is more likely if not certain to occur as a result of a previous history of polio and its residual effects--the nerve damage and the resulting muscle weakness.

I'd like to explain the difference between post-polio syndrome and post-polio progressive muscular atrophy (PPMA). The latter is a term that Dr. Marinos Dalakas, National Institutes of Health, Bethesda, MD, first used in one of his classic articles in The New England Journal of Medicine. In my experience PPMA is unique to a small number of polio survivors. In the chronic partially denervated muscles of people

with PPMA, the nerve function is progressively deteriorating, and the muscle is shrinking. One of the problems is that atrophy implies a smaller size of the muscle. Many times you can't see the shrinkage, and it's hard to know what the size was before. Certainly we, as professionals, cannot tell if it's smaller than it used to be unless we've done some serial measurements or known you awfully well for a long period of time.

Some people with a history of polio have lost some function as a result of a cluster of classic symptoms--pain, weakness, and fatigue. But pain, weakness, and fatigue can be symptoms of so many different problems. If the diagnosis is clearly known, this is a late effect of polio. The classic example is degenerative arthritis of the knee joint. The diagnosis is known, and the condition is treatable.

If that degenerative arthritis causes enough pain so that the person can't walk and the muscle gets weaker, the person then has to revert to a wheelchair, cane, or make major life-style adaptations. Because of weakness, loss of endurance, and loss of energy, they have a new disability (as defined by the World Health Organization--"any restriction or lack of ability to perform an activity in a manner or within a range which is considered normal...") and they fit the definition of post-polio syndrome. To me, post-polio syndrome is really a new disability.

This morning you learned about current research results, and I would highlight a couple. By most population studies, only a quarter to a third of polio survivors are likely to experience the post-polio syndrome or some new significant loss in function. It certainly is not an inevitable sequelae from having a past history of polio. Exactly what percentage will experience problems over the course of 40, 50, 60 years or an entire lifetime will

depend on what you define as a new problem and meets the definition of post-polio syndrome.

Certainly, one of the things we've learned in the last five years is that true progressive post-polio atrophy (PPMA), where there is rapid deterioration of nerve and muscle function, is very unusual. Exactly what percentage, again we don't know because population-based studies on that specific question have not been done. Neither has a definition been agreed upon.

Next, I would say that most of the new symptoms that people are experiencing have a specific known diagnosis. We have found in our clinic that you can specifically label the problems of the majority of people (bursitis, tendinitis, a tight muscle, other illness that caused deconditioning). Most of these conditions can be treated, but the causes are very complex. People come in, not as isolated pure subjects for research studies, but with all of their other health problems. They come to the clinic with all of their late effects, and then they may come with the classic (but not specific) symptoms of post-polio syndrome.

Another point that I would like to make is one concerning the issue of aging. Obviously, the polio population is not getting any younger. The more we study the questions of the late effects of polio, the more we have to acknowledge that much of what we're seeing is related to aging. It may be related to accelerated aging particularly of the muscles, joints, and nerves. But as the non-polio population gets older, they also have many more new health problems and a greater number of disabilities.

Another statement we can make is that exercise is in fact neither good nor bad. Exercise can achieve many positive results when it is done carefully and correctly. On the other hand, there is still the

issue of how much exercise is damaging for certain parts of the body.

Where is the post-polio movement now on this issue? I would say that the research efforts are beginning to mature. We have reached the stage where we have a recognized field of study. At the medical meetings of rehabilitation professionals, new scientific information about post-polio matters is regularly presented. Articles are being published in a variety of medical journals. Professionals in the field of rehabilitation, at least, are no longer saying, "What is this post-polio problem?" They realize that this is an area to be studied.

Admittedly, post-polio problems are not being studied to the degree that many of us would like, but it has reached a stage of respect. Unfortunately, there are still people in medicine who have not yet heard about it, and as we heard this morning, there are parts of the world where people have not heard.

I think we have to acknowledge our accomplishments but we have a lot of work ahead of us. I think we are still federally under-funded. We need to come together to focus on what are the priority areas for further research. Where do we really want to go with this area of post-polio study?

Besides the obvious need to continue spreading the knowledge of what we have already learned, we need to begin focusing on prevention. We need to investigate what can be done to prevent the problems occurring among a population who is growing older with a chronic disability.

I think what we are going to learn in our studies will not only benefit people with a history of polio but will benefit people with motor disabilities from other causes.

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We are going to learn more about aging. We have already discovered that we can't cure aging! What we can learn to do is to manage aging.

We are going to learn more about the impact of the environment and life-style choices on our health. Also, we will be able to relate the effect of psychological and social adaptations to physical disability to health in general.

My own intuition is that many of the problems we are seeing in some people with a history of past polio are health issues related to life-style--whether it is over-exertion, poor diet, smoking, or exposure to environmental toxins.

Problems are also related to attitude. When people get depressed, they perhaps overreact. How does that affect their health and physical decline? These are some of the things that I think we must learn and will want to apply as we now go into the next stage of the post-polio movement.

\* The International Classification of Impairments, Disabilities and Handicaps was published by the World Health Organization in 1980. Available for Swiss Fr. 15 from WHO Sales Service, 1211 Geneva 22, Switzerland or from local WHO bookstores.

### The Body And the Mind

By Jack Genskow, Ph.D., Sangamon State University, Springfield, IL

My role today is to aid in the transition from the medically, physiologically "Body" oriented morning to the more psychological "Mind" focus of this afternoon. There are different ways to approach this transition from physical to psychological.

First, the cognitive psychologists would point out that in adjusting to disability or any problem, it's

not the problem itself, but rather how one interprets the problem, or what you tell yourself about the problem, that causes the response. It's not the disability that causes adjustments or maladjustments; rather it's the way the person interprets that disability.

For example, you might have two people in the same room with the same disability. One person might be very depressed, very sad, and giving in, while the other person might be upbeat, optimistic, working hard on their rehabilitation. What's the difference? The first person might be telling himself or herself, "Oh I'm so sad, I'm so unfortunate, look at everything I've lost. My life's essentially over." The other person might be saying, "Hey, I nearly died; am I lucky to be alive! I'm going to work hard and try to make the most of things."

The cognitive psychologists say, "You don't have control over your disability itself, but you do have control over what you tell yourself about your disabilities. You can work on that and aid in your adjustment."

Another approach comes from the grief therapists. A therapist named Worden says that in dealing with any loss it's important to fully grieve your loss in order to fully adjust to it whether it be loss through death, loss of a relationship, or loss of physical abilities. Worden suggests four tasks that you need to work through for healthy resolution of your grief. These are tasks you can work on and that you have psychological control over.

The first task is to accept the reality of the loss. This may take time. The second, as you accept the reality, is to experience fully your emotional response to the loss, whether it be sadness, depression, or anger. These tasks go together.