Barrett's concept, which she calls power-as-knowing-participation, has four components, each of which has meaning for us: awareness, choices, involvement in creating changes, and freedom to act intentionally.

AWARENESS: By attending this conference, by listening to the speakers, and by networking with one another, we are increasing our awareness not only of change, but of some ways in which we can respond to it.

CHOICES: We are certainly faced with choices and are involved in making choices regarding our therapy, our life-styles, and our priorities. We can choose to seek help or not, to listen or not, to conserve our strength and ration our muscle function...or to go on a major energy-spending spree, flaunting and enjoying what we can do while we can do it. We can also choose whether or not our experiences will lead to personal growth.

INVOLVEMENT IN CREATING CHANGES: One of the important changes we can be involved with is how we respond to what happens in our lives. Maslow described self-actualization as the process of selecting the "growth choice" over the "fear choice" many times. He also noted that the most holistic levels of human consciousness seemed most frequently found in "heroic" people who had been strengthened, rather than weakened, by adversity.

FREEDOM TO ACT INTENTIONALLY: According to psychologist Al Siebert, people who take an active role in responding to personal trauma are among "life's best survivors." We <u>are</u> free to act intentionally, selecting health professionals to work with us as we make choices about our rest and exercise, eating habits, use of orthotic aids, ways to minimize our pain, and maximize our energy, and our physical abilities. And it seems to me that many of us are indeed among the group called "life's best survivors."

As knowing participants in change, each of us is empowered to participate in changes in the manner and direction we value. I urge my friends who have also had polio to take an active role in your health care. Be aware. Become knowledgeable. And make the choices that work for <u>you</u>, reflecting your own values and priorities.

I would like to close with a plea to my fellow health professionals to hear us. We are trying to learn to swallow our pride and ask for help. We are working to overcome years of conditioning that we are "the lucky ones," that others need help more than we do, and that to ask for help is to admit failure. When we do realize that we need help and finally reach out to you, please hear us, believe us, and work with us. Together we can find a way for us to continue to enjoy meaningful, productive lives with our sense of self-esteem intact.

<u>NEUROLOGICAL RESEARCH *</u>

By Raymond Roos, M.D., University of Chicago, Chicago, IL

I want to discuss three research directions we are involved in at the University of Chicago. I'll very briefly describe: analyses of the neuromuscular junction (the nerve and muscle junction) in post-polio individuals; studies looking for immunological or virological abnormalities in post-polio individuals; and molecular studies of the poliovirus and related viruses to learn more about why motor nerve cells die.

But first, let's review a previous study that tried to answer questions still very much on our minds. What laboratory studies differentiate post-polio syndrome individuals from post-polio individuals who have no new weakness or functional disturbance? How can we make the diagnosis of post-polio syndrome from a laboratory point of view?

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What's the cause of post-polio syndrome?

While still at the University of Chicago, Dr. Neil Cashman led a group of investigators, including the moderator Roberta Simon and me, in studying post-polio syndrome. We performed muscle biopsies and electrical studies on post-polio individuals with and without post-polio syndrome. As a result of the studies, we can report these findings.

First, no laboratory study presently available differentiates post-polio individuals from non-weakening post-polio individuals. In other words, we could not detect a statistical difference between these two groups with respect to findings with conventional electrical studies and muscle biopsy--because there is ongoing nerve damage in members of both groups (non-weakening as well as weakening post-polio individuals). We also found that the ongoing denervation was associated with very large motor units. Let me explain the origin of these large units. In acute poliomyelitis some motor nerve cells that innervate muscle fibers die. The remaining living motor nerve cells have to take over a larger number of motor fibers, and consequently these motor nerve cells have to do more work. The large units seem to be associated with progressive nerve problems. One question is whether terminal sprouts of the motor nerve cells die or malfunction causing the denervation.

We decided to try to examine the sprouts using a biopsy of the anconeus muscle (small muscle in the forearm), since it can be used for sophisticated neurophysiological research. Dr. Ricardo Masselli of the University of Chicago and I are very much involved in this study now. In fact, we are interested in recruiting post-polio patients for the biopsy study.

Dr. Robert Wollman is looking at the actual terminal sprouts of the motor nerve itself to investigate whether they show anatomical abnormalities. We are able to do electron microscopy to look at the actual terminal nerve sprouts as well as the muscle itself and the neuromuscular junction. The neuromuscular junction is abnormal in the case of another neuromuscular disease that shows fatigue (like the post-polio syndrome) as a prime clinical symptom--myasthenia gravis. Our preliminary studies show that the neuromuscular junction of the anconeus muscle of a post-polio individual appears very different from normal. We are midway in these studies and currently analyzing this data. We are looking very carefully in an effort to determine whether the terminal sprouts or neuromuscular junction is a critical site in the development of post-polio syndrome.

Now let's talk about the relationship of the post-polio syndrome to a viral or immune abnormality. It's interesting to note that viruses similar to poliovirus can persist for a long time in the central nervous system. However, there is no evidence that poliovirus can persist. Although I do not believe that a virus is present in post-polio syndrome individuals, it is important to look carefully and scientifically at poliovirus persistence, especially since at least one investigator reported abnormalities of the immune system in post-polio syndrome individuals. He found bands of immunoglobulin in the spinal fluid after electrophoresis, a very common finding in multiple sclerosis spinal fluid. Dr. Edgar Salazar and I just completed a study looking at the spinal fluid in post-polio individuals. Out of the twenty spinal fluids that we looked at, none of the individuals had bands except for a patient who also had multiple sclerosis. In other words, we found no evidence of any immune abnormality in this study of

post-polio syndrome, and we were unable to confirm the findings of the previous study.

Lastly, we might ask the question, "What can the study of poliovirus infections teach us in a very broad sense about post-polio syndrome?" One of my interests is to learn about factors key to the survival and death of the motor neuron itself. Remember the poliovirus is very selective. The virus only infects and kills motor nerve cells. We should remember that the living vaccine that is presently given to prevent polio is also a live poliovirus. It replicates in the human body, but it does not paralyze.

Other investigators have cloned and sequenced the parental paralytic strain and the Sabin vaccine strain of poliovirus as well as paralytic revertant mutants that rarely arise after vaccination and may cause poliomyelitis. We now know that the vaccine strain that Sabin developed has mutations that occurred during passage of the parental paralytic strain. Investigators can now "mix" the Sabin vaccine strain with the parental strain and make recombinants of the genes. Each of these recombinant genes can be made into a virus which can be tested to determine how paralytic it is. As a result of these experiments, we now know exactly what the key mutation is that makes the paralytic parental strain a non-virulent vaccine strain. In other words, the part of the genes of this virus, as well as viruses related to poliovirus, that causes paralysis or death of motor neurons has been identified. This knowledge is important in our understanding of which genes and gene products kill motor nerve cells and the mechanisms involved. In addition, these studies will be important in making the "perfect" poliovirus vaccine. We have very good vaccines, but as a result of this kind of work, we will be able to make changes in the genes so that the vaccine will "never" generate a revertant that can cause poliomyelitis.

* This article is a revised version of the transcribed and edited remarks published in Polio Network News (Vol. 5, No. 4).

FOR YOU TO CONSIDER

A HYDROTHERAPY PROGRAM FOR PATIENTS WITH POST-POLIO SYNDROME

By Lynette Jenkins, M.C.S.P., M.C.P.A., O.N.C., Toronto Rehabilitation Centre, Toronto, Ontario, Canada

Post-polio survivors referred to the Toronto Rehabilitation Centre from Dr. William Franks and other physicians in Toronto are assessed by the Centre's own physician, an occupational therapist, a social worker, and a physiotherapist.

THE POOL

The pool is approximately 30' by 18', with a "stepped" floor providing four depths, 2'6", 2'11", 3'5", 4'5". Access is either by shallow steps or by a mechanical hoist. The temperature of the water is kept at approximately 96 degrees Fahrenheit. The pool is equipped with "furniture," consisting of aluminum chairs and parallel bars.

The Hydrotherapy Program

Polio-affected muscles are weak and in some cases paralyzed. This can lead to a tightening or even a contracture of the affected tissue. Slow, gentle stretches, always within a pain-free range, help to alleviate this tension, reduce contractures, and relieve cramping. While it may be impossible to strengthen muscles affected by polio, it is possible to strengthen the unaffected muscle groups. Very often extra strain is exerted on them, and so strengthening routines can help prevent damage because of the overload.

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