

UPDATE FROM CZECHOSLOVAKIA

By Alois Wokoun, Chabarovicka 133,
Prague 8 - 182 00, Czechoslovakia

I enclose my contribution to the Fifth International Polio and Independent Living Conference the results of my survey of 12 Czech polio survivors as to the late effects of their polio.

Twelve polio survivors (five women and seven men) from Bohemia, the western part of Czechoslovakia, born in the years 1924-1939 and affected by polio in 1932-1949, have been questioned about their late effects of polio. The survivors range in age from 49-64.

Ten of them have begun to feel new weakness of muscles which were originally affected by polio. (Six of these are not yet 60 years old.)

Seven of them have begun to feel increased weakness of muscles which were originally not affected by polio. (Four of these are not yet 60 years old.)

Eleven of them have begun to suffer from joint pains 35-50 years after polio. (Six of these are not yet 60 years old.)

Other problems include "flu-like" aching in muscles, shortness of breath, partial muscle cramps and fasciculations, muscle tingling, and sleep disturbances. Age differences, as well as sex differences of the respondents, have not influenced the late effects of polio in this examined group of polio survivors.

Fifty-eight percent of the questioned polio survivors had 3-4 limbs affected by polio in the acute stage, but 1-2 limbs remained paralyzed after subacute treatment. In forty-two percent of the respondents, the originally affected limbs have remained paralyzed.

I share information about your organization and the conference with polio survivors and therapists during my treatment at Czechoslovak Janske Lazne Spa.

Research--Is It for You?

By Roberta Simon, RN, Darien Park, IL

Research is an important aspect for the medical community in dealing with any health difficulty which has no previous history of known causes or treatments. Unfortunately, as we are all aware, post-polio syndrome falls into this category. Since many of us have been or will in the future be asked to participate in research, I think it is wise for us to consider a few questions and options.

Of course, the first consideration is what the physician conducting the research hopes to learn. You would also want to know if there is a risk to you by participating in the research and if there would be any charges to you or your insurance company. Most research is funded totally by either a grant or the institution conducting the research. All research plans must be reviewed by that institution's review board for the use of human subjects so that they can evaluate the ethical use and the amount of risk to the prospective participant. These results should be available to you if you inquire.

You will also want to know how many visits the research will require and evaluate your personal situation to see if this is a possibility for you. Some research programs require only yearly evaluations. Others may require weekly or even more frequent visits. If this is the case, are you willing and able to cooperate? This follow-up is extremely important to the physician or institution, so try to be fair in evaluating this aspect.

Would the results of this research benefit your treatment in any way? Would it improve your function and slow the progression of post-polio syndrome? Or would it give clinical information that would be of benefit only to other clinicians trying to determine the cause of the problem? I don't mean to imply that this is not important, because answers often come from the knowledge gained by understanding the cause.

Last, but certainly not least, is the consideration, "Is this procedure invasive?" Muscle biopsies or spinal fluid studies are invasive and increase the risk to the subject. If you participate in such a study, you might want to be informed not only of the risks, but also who will finance the treatment and costs if complications occur. Exposure to radiation is also an important consideration. If this type of study is proposed, be certain to discuss it with your family physician or primary caregiver. If you are having numerous x-ray studies for other health problems, this may not be the study for you.

Research holds the key to understanding and treating post-polio syndrome, and we should all try to contribute in some small way to finding these answers. If you feel uncomfortable with participation in one research study, don't feel guilty or embarrassed to say no. There will be other possibilities, and perhaps another would be better for you. Remember: you are in control, and the decision is yours.

From New Mexico

"Controlling Pain and Fatigue" is being published in many group newsletters without mention that it is an outline of a video I made last spring. The outline was intended to be used with the tape which is available on loan or can be purchased for \$6.10 which covers the cost of the blank tape and mailing.

I am honored by the response to the outline, but in the tape I make it quite clear that I am not a medical professional and urge everyone to check with a physician before trying one of the "tips." Also, I wonder how well newsletter editors are checking the sources of their information to avoid misinformation.

Since my diagnosis of post-polio sequelae, my husband Frank and I have been dedicated to helping polio survivors. We have noticed a lack of information in the following areas: When did you first notice a symptom that led you to seek medical care? Have you had bladder problems? Have you had digestive problems? I am interested in collecting information in all areas that cause you distress.

Caroleanne Green, New Mexico Polio Survivors Organization, 1008 Ivydale Drive, Las Cruces, NM 88005.

From British Columbia

An order form for audio tapes of MANAGING POST POLIO PROBLEMS, the November 1989 polio conference in British Columbia, is available from PPASS Office, 813 Darwin Avenue, Victoria, BC V8X 2X7, Canada.

During the recent First Pacific Northwest Regional Polio Conference, in Richmond, BC, I met with polio survivors who had had paralysis of the throat and/or face.... We had several concerns. How do we maintain the function we have? How do we keep from deteriorating? We also had several things in common. We all have swallowing problems, choke easily, grind our teeth, and have varying degrees of hassles with other people's attitudes. I would appreciate receiving comments.

Sieglinde Stieda, 2790 West 21st Street, Vancouver, BC V6L 1K4, Canada.