POLIO NETWORK NEWS

International Polio Network

4502 Maryland Avenue St. Louis, MO 63108 U.S.A. 314/361-0475

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

Annual Membership: \$8.00 (USD* only) for polio survivors. \$15.00 (USD only) for health professionals. (Add \$3.00 for postage outside the U.S. and Canada.) *U.S. Dollars only

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Questions and Answers

QUESTION: "Who establishes the post-polio clinics in the States and how are they organized?"

Henri Charcosset, Villeurbanne, France

ANSWER: To establish a post-polio clinic, a need has to be perceived for such a clinic. This perceived need may be generated by the medical community, but more likely the catalyst will come from the demands of the post-polio population, in particular, the support groups. A post-polio clinic can be organized if the appropriate expertise exists in the community. The best resource is a rehabilitation center which has a full complement of professionals able to meet the various aspects of the post-polio survivors' special needs in a coordinated fashion.

These professionals should be led by a physician specially trained to meet the needs of individuals with physical disabilities. A physiatrist whose formal training is a residency program in physical medicine and rehabilitation is best qualified. There are some cases of other physicians who also have developed a special interest and expertise in helping individuals with disabilities.

The multidisciplinary treatment team should also include a physical therapist, occupational therapist, speech therapist, recreational therapist, rehabilitation psychologist, rehabilitation social worker, rehabilitation nurse, a dietitian, orthotist (brace fabricator), and a vocational counselor. There should be access to specialists in pulmonary medicine, neurology, and orthopedic surgery.

One person in the rehabilitation center should be designated to coordinate the clinic program. His or her responsibility is to assemble the many medical professionals described above who will dedicate part of their practice to the post-polio clinic. The selected personnel will need to develop the special expertise to evaluate and treat individuals with post-polio

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Questions and Answers

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syndrome by examining the literature, attending seminars and conferences, or by visiting an established post-polio clinic. (Consult the Post-Polio Directory or call International Polio Network.) The team members will need to be well versed in treatment techniques utilized in the past as well as newer protocols for the polio survivor.

Preliminary planning meetings of all disciplines are essential to (1) define roles, (2) establish goals, (3) determine treatment approaches, and (4) evaluate outcomes.

In our post-polio clinic at St.
John's Mercy Medical Center in St.
Louis, the client completes a medical history information sheet prior to the initial evaluation. The client is then seen by a physiatrist who will review the client's medical history and perform a thorough neurologic and musculoskeletal examination. When appropriate, further evaluations by the treatment team will be arranged.

One member of the treatment team, a physical therapist (P.T.), measures range of motion, strength, and assesses mobility status. Based on the outcome of this evaluation, an individualized treatment is established to maintain or increase strength, to improve range of motion, to relieve pain, and to maximize mobility skills. An assessment may also be made to determine the need for ambulatory aids.

An occupational therapist (O.T.) evaluates daily living skills including an assessment of self-care and home management capabilities. This treatment may include instruction in energy conservation techniques and work simplification as well as suggestions for adaptive techniques and equipment to maximize the individ-

ual's participation in home and work activities.

A speech therapist assesses any speech or swallowing difficulties, and therapy is developed to maximize communication and safe swallowing skills.

A clinical rehabilitation psychologist provides individual and family counseling. The primary focus of counseling is to identify coping styles and to assist in learning to adjust to necessary lifestyle changes. Nutritional counseling is provided to assist persons requiring therapeutic or weight-reduction diets.

A recreational therapist assists clients in maximizing their recreational and leisure skills.

A rehabilitation nurse makes home visits and offers suggestions to make a client's home as accessible and functional as possible.

A rehabilitation social worker informs clients of the community resources available to them. When appropriate, the state department of vocational rehabilitation (VR) is contacted to provide vocational counseling including work evaluation. VR can facilitate appropriate job training to assist a client to return to his or her former job, even if adaptive equipment is necessary. Alternate job training and placement also may be arranged.

An orthotist works with the rehabilitation physician and the therapists to repair or modify older orthoses. In addition, the orthotist may fabricate new custom upper extremity, lower extremity, or spinal orthoses often using the latest light-weight plastics to maximize function, attractiveness, and comfort.

After the client has been through the appropriate evaluation and treatment program, the clinic staff will collaborate to ensure that all of the special needs of the client have been addressed. If not, the coordinated treatment program will be modified. The client will usually return for a follow-up physician appointment in one to two months to assess the success of the program and to make sure the client's perceived needs and the needs perceived by the professional staff has been met. If needed, further evaluation and treatment is then prescribed.

The initial evaluation is done on a Monday so individuals traveling long distances have the opportunity to travel over the weekend. We do arrange for overnight stays at a minimal cost. With an out-of-town client an attempt is made to do the entire evaluation in one or two days with rest periods provided. The majority of our clients are within driving distance of our medical center so we set up the various professional appointments over several days to minimize fatigue.

We encourage our clients to join their local post-polio support group as peer interaction and support is an important complement to our program. We also encourage our clinic personnel to give lectures and to lead discussions at support. group meetings in the surrounding area. The education of the client is a key part of our clinic. Handouts have been developed explaining work simplification, energy conservation, and home exercise programs and describing durable medical equipment options with sources of supply. Other appropriate handouts to meet any special need of the client are also available. We provide the Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors both to the client and, if appropriate, to his/her primary care physician.

Reimbursement for services is a billable item to the insurance companies within the guidelines of the client's policy. The ever-changing

climate in Medicare, Medicaid, and various insurers continues to be a challenge for the consumer, physician, therapist, and the hospital. In order to receive the entitled benefits, consumers should be very familiar with their coverage.

Our clients have found that our clinic has given them an avenue to express their fears and frustrations and the means to address their special physical, phychological, and social needs. The clinic personnel have found the sharing of their expertise a rewarding experience.

Post-polio clinic personnel of St. John's Mercy Medical Center, St. Louis, MO

QUESTION: "What Methods Have Groups Used to Compile Physician Registries?"

Sylvia Meek, Cincinnati, OH

ANSWER: The first step in locating knowledgeable physicians to work with your group is to poll your group. You may find that some of your members have a physician who is managing their difficulties quite well and is very knowledgeable.

The next step is to locate all the physiatrists and neurologists in your area that have experience in dealing with neuromuscular disorders. Contact your area hospitals and ask if they have staff physicians with these skills. Then contact the physicians and discuss with them the post-polio problem and the needs of your group.

If you are financially able, send them International Polio Network's (IPN) Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors to read. You may also refer them to other physicians in the country who are seeing polio survivors or have published medical

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