

POST-POLIO FOLIO

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PRESIDENT'S REPORT TO THE FALL '88 GENERAL MEETING OF THE QPPSA.

*Speech delivered by
Mona Arseneault, Presi-
dent.

We come together as polio survivors or family or friends of people with polio. This association was formed because of a medical need, but now I realize that we need each other whether or not we have a medical reason. President Franklin D. Roosevelt recruited a whole country in the 30's by asking for dimes. We must work together to find our solutions to today's medical problems.

Many people are already working very hard this year on several new projects. We have:

- 1) A Newspaper Team about to produce a bulletin.
- 2) A Financial Committee to find a suitable fund-raiser.
- 3) Mini Self-help groups.
- 4) A Bilingual Phone Team that is growing.
- 5) The beginnings of a Polio Library.
- 6) A Medical Clinic that may soon be a reality.

Thank you. ☐

**THANK YOU, MONIQUE
GREGOIRE, AND HAPPY
BIRTHDAY (February 15)**

In 1985 when Polio-Quebec was just beginning, Madame Monique Gregoire volunteered long hours on the telephone listening to and helping people who needed information and assistance (in french) Because of ill health and with much regret, Monique had to give up this job, but her constant interest in QPPSA is proof of her caring for all polio survivors.

HELP????????????????????

Reading the folder indicating the focus of the QPPSA, you will find

a) Services available, aimed at improving the quality of life of persons with post-polio syndrome.

b) Research into the treatment and a possible cure of post-polio syndrome.

No doubt the medical aspects are the most important and require our utmost attention. This service is under the guidance of Dr. Cashman* and his team.

How can we improve the quality of life of our members out-

side the pure medical field. Indeed, small but frustrating incidents, such as changing a light bulb, are difficult, even impossible at times for certain of our members. Nevertheless, they hesitate to disturb people readily available, ~~in~~ outside the family circle. On the other hand, we have cases where a house must be converted for wheelchair access (larger doorways, ramps instead of stairs, adapting kitchen and bathroom). To find qualified professionals for such jobs is often difficult and usually expensive.

It is in this direction that we aim our services, by creating an "Administrative Coordina-

We would like to express our utmost gratitude for all she has done, and our admiration. In spite of the greatest of difficulties, she has been a success, both as a mother of two sons as well as a scientist (physiology).

Monique, we applaud your many achievements and are inspired by your courage. May you keep finding happiness and peace of mind amongst those who love you and care for you. ☐

tion" center, where SUPPLY and DEMAND will be exchanged. The "demand" side is simple. The member requesting assistance contacts the

(continued on page 3)

... the Cashman's telephone as an insert

mini-group. The "supply" side is a bit more complicated. We want to set up teams in each sector (mini-group) based primarily on volunteers, but assisted by a corps of professionals, including members who could help by using their experience.

Volunteers should mainly come from the family of the members. We are looking for people who are familiar with the day-to-day life of our members and who are ready to help others who do not have such immediate assistance available.

Once the QPPSA has this team, it can then go and exchange "sweat-equity" with existing groups working on similar projects within the same geographical area.

Any suggestions? Complete enclosed reply coupon(s), communicate with the leader of your mini-group, or better still, come to the next monthly meeting of your group. ☐

SUMMARY OF A SCIENTIFIC REPORT

I thought it would be of interest to members of QPPSA to present summaries of articles about the late effects of polio, physically and/or psychologically. This first article is about STRESS AND TYPE 'A' BEHAVIOUR AS PRECIPITANTS OF POST POLIO SEQUELLAE: The Felician/Columbia Survey, by Richard L. Bruno and Nancy M. Frick.

This research demonstrates that people who have polio are usually Type "A", i.e., they experience chronic emotional stress. It also shows that post-polio sequelae is precipitated or exacerbated by stress.

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•SPECIFIC RECOMMENDATIONS FOR POST-POLIOS

•DO'S AND DON'TS

•GENERAL THERAPIES AND THINGS TO AVOID

What follows is a general, practical guide for those who have had polio. It summarizes in outline form the current thinking about post-polio. It is not a substitute for individual medical evaluation or therapy. It will be most valuable if it stimulates you to seek further and more specific information.

Try to maintain a positive attitude toward your health; accept change, adapt, and never equate your self-worth with physical disabilities.

If you are experiencing increasing muscle weakness, exercise only under the supervision of a knowledgeable physician.

Medical evaluation of people who have had polio should include a complete history, physical exam, and appropriate lab studies.

Muscle strength evaluation should be done by a registered physical therapist or someone familiar with neuromuscular diseases.

Repeat muscle testing is now advised every year, even if there is no obvious change in strength.

The current recommendation is that all those who have had polio have a complete medical evaluation covering the three major areas affected by polio: neuromuscular, circulatory, and respiratory.

Make sure you get adequate nutrition.

Be alert to (not obsessed with) changes in your body, and heed your body's signals.

Take note of any new symptoms plus clear or gradual changes.

Get enough exercise to prevent disuse atrophy, but not enough to produce overuse damage.

Learn how to pace yourself.

Prevent the secondary complications of weakness, particularly falls; this might entail the use of crutches or a cane, or a wheelchair for extended travel, or braces or other adaptive equipment.

People who have had polio MUST learn to conserve energy. Those who have had polio, even though once rehabilitated, must be re-evaluated and learn new techniques to replace those that no longer work.

Body positioning during sleep is important for those with severe weakness, postural or joint deformities.

Those with marginal respiratory reserve should consult a qualified physician before travelling to significantly higher elevations.

Avoid weight gain; too much weight only aggravates stress on joints and muscles.

Consider possible adaptations to your life style; even minor adjustments - changes in hobbies or modes of transportation - can help.

Do not assume that every physician fully understands post-polio problems; educate yourself, and never hesitate to ask questions.

Minimize alcohol use, particularly at bedtime; alcohol inhibits swallowing, interferes with nutrition and causes falls and other accidents.

What is Type "A" behaviour?

It describes a person who is "competent, hard-driving and a time conscious overachiever who demands perfection in all aspects of his personal, professional and social life." The authors are wondering why people who had polio seem to be of Type "A". One of the hypotheses is that if a handicapped person wishes to succeed in a barrier-full society, he/she must learn Type "A" behaviour, i.e., physical limitations demand awareness of the extra amount of time it takes a handicapped person to perform a routine task.

"Social prejudice might require persons with disabilities to become hard-driving over-achievers, personally, professionally and especially physically, to be accepted by peers and employers." (p. 152)

Further in this research, the authors speak about the effects of stress on animals, i.e., stress accelerates the onset of muscle fatigue and shortens life-span.

Stress, associated with aging, decreases terminal axon branches innervating muscles. This phenomenon might be "responsible for the shrinkage of motor units seen in persons who had polio [...] and has been implicated as a probable cause of post-polio muscle weakness."

The authors then describe the effects of the corticosterone hormone, which I will not elaborate on in this summary.

The study emphasizes the predominant role of stress in post polio sequelae and how this stress can be treated by a proper stress management program.

It seems appropriate to follow this summary with a few words about RELAXATION. After all, we can sleep without being relaxed just as we can sleep without sleeping. A relaxation

period of 20 minutes in the morning and/or afternoon will help you be more energetic all the day long. I know from experience how helpful it is. There are many relaxation techniques. It is most important to choose a method which makes you feel comfortable. There is also a choice of tapes about relaxation.

To relax successfully, don't pressure yourself into doing it at the first session. Practice regularly and you will succeed. If you don't know how to begin, look for an instructive book in your library or ask advice at your local CLSC.

Good luck!

Celine Bourget, psychologist —→

P.S. If you wish to contribute scientific summaries of articles or books dealing with some aspect of polio which would interest QPPSA members, your help would be welcome. We have a lot of information, and we would appreciate assistance in reviewing and/or translating. Don't hesitate to contact me at 521 5708.

(Recommendations cont'd)

People who have had polio and have respiratory insufficiency should take common colds very seriously.

Get enough bulk-producing fiber in your diet. Avoid stimulant.

Take time to rest; nap if possible during the day, work fewer hours, take longer vacations.

Problems with extremities or joint function may require special consultation - from physiatrists, orthopedists and/or neurologists - familiar with skeletal deformities and muscle weakness.

Experienced physical or occupational therapists can help determine functional losses and how best to adapt

Muscle stretching and joint range-of-motion exercises are important where there is muscle weakness.

Swimming is the best cardiovascular endurance and general conditioning exercise. Water temperature should be warm. Discontinue any exercise that causes pain, weakness, or muscle fatigue, including walking. Muscles weakened by polio respond poorly to vigorous strengthening programs. Such programs - weight lifting, for example - often aggravate the condition. People who have had polio should know their own strength limits or endurance and avoid going repeatedly to that limit.

Occupational therapists can help assess upper extremity function, daily activities, and need for assistive devices - all to help achieve the highest level of independence possible.

Rest is one of the best known treatments for aching muscles. Moist heat, anti-inflammatory medication, and avoiding exertion are also helpful.

Physical therapy (heat, massage, joint mobilization and stretching exercises) under the direction of a physician knowledgeable about post-polio can help chronic lower back pain. Change of gait pattern such as using crutches, may be needed to prevent recurrence of lower back pain.

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