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STAY WELL!



The Polio Network's
Manual For A Health Promotion Program

Edited By:

SUNNY ROLLER, M.A.
FREDERICK M. MAYNARD, M.D.

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With a Special Foreword by:

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International Polio Network**

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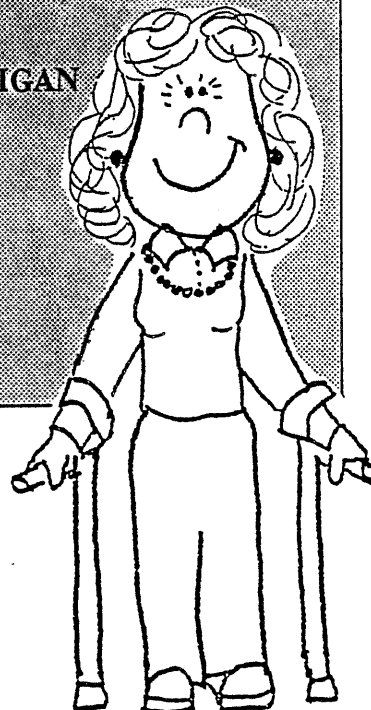
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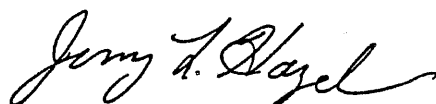
We of the Polio Network, Inc., take a great deal of pride in introducing you to the STAY WELL! manual. We have spent a number of years supporting research concerning the needs of people who are having post-polio problems. The major part of the research that we have used as a basis for this handbook has been sponsored by the Post-Polio Research and Training Program at the University of Michigan Medical Center. This program, directed by Dr. Frederick Maynard and coordinated by Ms. Sunny Roller, has promoted and generated many studies by University of Michigan faculty and others on polio's late effects.

Our Polio Network is making a major shift in direction--from information-gathering to help-giving. With all of the information that we have at our disposal, we hope that we may now have the "tree of knowledge" bear fruit.

As this is a serious undertaking, we are moving very carefully. With the contents of this manual, we feel that we are addressing three major problems of most people who have disabilities. Used as a basic format, the handbook should help you set up programs that will promote better health and a stronger sense of well-being among polio survivors.

May we wish you the best of results as you put the guidelines set forth in this publication to work in your community.

Take care and best wishes,



*Jerry L. Hazel, Chairman
Polio Network, Inc.*

About the Editors

Sunny Roller, M.A., a polio survivor, has been the Coordinator of the Post-Polio Research and Training Program at the University of Michigan Medical Center since 1986. She is a co-founder and co-coordinator of the Post-Polio Connection, a support group for polio survivors and their friends and families in Ann Arbor, Michigan. She has been an active participant on the Board of Directors of the Polio Network, Inc., serving Michigan. In May 1987, Ms. Roller received an award from Michigan's Kenny R.E.H.A.B.: "A Person with a Disability Whose Achievements Are an Inspiration to Others." She wrote and developed the videotape entitled "Coping Successfully With Polio's Late Effects" (March 1989), which was reviewed as being lively, insightful and concretely useful for consumer and professional audiences. She has authored "Post-Polio" in *Accent On Living* (September 1990) and, with Dr. Frederick Maynard, co-authored "Recognizing Typical Coping Styles of Polio Survivors Can Improve Re-Rehabilitation: A Commentary" in the *American Journal of Physical Medicine and Rehabilitation* (April 1991). She has also co-authored several published abstracts concerning the late effects of polio.

Sunny toured India in January 1990 as part of a team lead by Dr. Maynard, and participated in the "All-India Conference on Polio Eradication and Post-Polio Rehabilitation" in Kerala, India, presenting information on post-polio re-rehabilitation and its implications for people in developing nations. Ms. Roller continues to be an invited speaker at statewide, national, and international conferences. She addresses consumer and professional audiences on various post-polio topics, including: resources available through the post-polio network, emotional responses associated with the late effects of polio, and effective post-polio adjustment strategies. Ms. Roller will also serve as a consultant on post-polio organizational development and wellness programming, upon invitation.

Frederick M. Maynard, M.D. is Associate Professor of Physical Medicine and Rehabilitation at the University of Michigan Medical Center. He founded the Post-Polio Clinic at University of Michigan Hospitals in 1984 and has continued to evaluate and manage hundreds of polio survivors, along with the clinic's co-director W. P. Waring, M.D. He has authored numerous publications concerning the late effects of polio, including "Differential Diagnosis of Pain and Weakness in Post-Polio Patients" in *The Late Effects of Poliomyelitis*, the *Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors*, and "The Late Effects of Polio Create Large Demand for Re-Rehabilitation" in *Rehabilitation Report*.

Since May of 1986, Dr. Maynard has been awarded several grants to study the late effects of polio and to train professionals and consumers about those effects. His most recent project, sponsored by the Centers for Disease Control, was a study of the prevention of secondary disabilities among people with polio. Dr. Maynard has served on the program planning committee and been a speaker and participant at all the Rehabilitation Gazette Conferences on Polio and Independent Living. He was elected to the Board of Directors of the Gazette International Networking Institute in 1991. Dr. Maynard was a founding board member of the Polio Network, Inc., serving Michigan in 1986, and was an invited participant at two Research Symposia on the late effects of polio at Warm Springs, GA. In January 1990, Dr. Maynard and a team of rehabilitation specialists participated in the "All India Conference on Polio Eradication and Post-Polio Rehabilitation" in Kerala, India. Dr. Maynard continues to be a popular invited speaker at professional and consumer conferences around the world, serving as a well-known international authority on polio's late effects.

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...but most of all...spirit.
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A special thanks
to
Josephine Strauss

for initiating the first post-polio wellness program in
Mt. Pleasant, Michigan.

Foreword

In 1981, an international conference of polio survivors and health professionals was appropriately named "Whatever Happened to the Polio Patient?" The historic meeting challenged survivors to "wake up to who and what (they) really are--leaders." They were called upon "to organize and to make a commitment to action."

During the last 10 years, thousands of survivors have done just that. Experiencing the classic symptoms of pain, weakness, and fatigue, and in some cases, breathing and swallowing problems, survivors also realized that many of these symptoms have far-reaching consequences. The late effects of polio can include exasperation with the health care system, re-examination of personal feelings, re-negotiation of family relationships, and anxiety over possible unemployment.

Survivors have learned from survivors; health professionals have learned from survivors; survivors have learned from health professionals.

Committed polio survivors and caring health professionals are meeting the demand for solutions by creating a unique, worldwide network of assistance comprised of community-based support groups. Survivors have learned from survivors; health professionals have learned from survivors; survivors have learned from health professionals. The self-help philosophy--asking for help, receiving help, and giving help--still serves them well. However, much of the emphasis continues to be on treatment for survivors in crisis.

Thankfully, the authors of STAY WELL! recognize that survivors who have been re-rehabilitated are in need of continued care and encouragement...

Thankfully, the authors of *STAY WELL!* recognize that survivors who have been re-rehabilitated are in need of continued care and encouragement and that survivors who are not having problems at the moment are seeking preventive guidance and reassurance.

The easy-to-use manual is indeed worthy of attention from all members of the polio network worldwide.

The accumulated scientific and experiential knowledge of post-polio problems has been integrated into this comprehensive program plan to promote good health and wellness for polio survivors. The easy-to-use manual is indeed worthy of attention from all members of the polio network worldwide. It provides step-by-step directions on how to design, organize, and initiate a community-based wellness program. It also includes extensive guidelines for ideas and activities regarding sound nutrition, healthy exercise and general lifestyle enhancement concepts that are relevant and applicable to the individual needs of polio survivors who participate in this community-based wellness program. This manual is written for use by both program organizers and facilitators. The program it outlines encourages polio survivors to further commit to take action--it challenges them to stay well.

I salute the authors for this timely publication.

*--Joan Headley, Executive Director
International Polio Network*

Preface

Polio survivors who are aging with long-term motor impairments are now part of a growing new population of people who have become neglected as health care recipients. Based on new figures from the National Center for Health Statistics, there are an estimated 640,000 survivors of paralytic polio living in the United States today. At least 22 percent of these survivors can be expected to experience declining functional capacity as a result of new health problems.

Often, polio survivors have become unnecessarily victimized...by the very limited opportunities for the same health maintenance and preventive health care that are readily available to members of the non-disabled population.

Often, polio survivors have become unnecessarily victimized not only by their vulnerability to alarming and unexpected new medical problems, but also by the very limited opportunities for the same health maintenance and preventive health care that are readily available to members of the non-disabled population.

Polio survivors justly desire and deserve to maintain lifestyles that are as fully functional, diverse, and independent as possible.

This group's new medical conditions and related secondary disabilities represent a previously unrecognized and growing American health care problem that must be addressed as more and more individuals live longer, more active and productive lives with long-held paralyzing conditions. Polio survivors justly desire and deserve to maintain lifestyles that are as fully functional, diverse, and independent as possible.

In the 1988 report "Needs Assessment of Polio Survivors in the State of Michigan," prepared by the UMMC Post-Polio Research and Training Program for

the Michigan Department of Public Health, the second greatest need reported by polio survivors themselves (following a primary need for more knowledgeable physician care) was that of self-education. Learning about proper health care, legal concerns, and financial assistance were high priorities.

"The program works!" declares participant Margaret Lloyd.

Polio survivors in the Polio Network, Inc. have publicly expressed a need to learn more about nutrition, exercise, and stress management techniques. Group support has been reported to be very beneficial to those who have found it through pilot health promotion programs. "We are learning to take charge of our own lives. We make decisions that are good for us," reports Dorothy Gowen of the Post-Polio Penguins, a self-help group in Toronto which evolved as a result of a pilot health intervention program using hydrotherapy. In Mt. Pleasant, Michigan, a pilot health promotion program, "The Jo Strauss Post-Polio Program," demonstrated that swimming and nutrition interventions along with a time for personal sharing can reduce body fat and improve polio survivors' well-being. "The program works!" declares participant Margaret Lloyd. People lost weight and felt better as a result of the group activities. Programs like these must be expanded to include all polio survivors who would like to participate in such a customized wellness program.

This manual has been created to provide the foundation for a feasible community-based health promotion program. With an emphasis on wellness and the prevention of new disabilities, it outlines a program that could be held in any community that has the appropriate facilities and a group of enterprising leaders who are willing to initiate and coordinate the program's activities. It presents an action plan for helping willing participants to improve and optimize their emotional and physical fitness levels. The curriculum is divided into three major areas: nutrition, exercise, and lifestyle enhancement. The triangular motif throughout this manual symbolizes that three-pronged emphasis and the importance of a healthy balance of all three areas.

The contents of the manual were created by a national team of "post-polio specialists" to be "user-friendly" and adaptable to facilitator and participant needs within the scope of minimally required resources. It is written for the organizers who will initiate the program, and for the facilitators who will make it happen. It is

dedicated to all of the potential participants who have fought so hard for decades to masterfully integrate the effects of polio and who ultimately have the power to make this program work...

Now, it is simply time for us to keep up the good "wellness work." Although there are no known cures, there are, indeed, remedies for our distressing late effects of polio. The program outlined in this manual offers us some of those solutions. The results are up to us.

--Sunny Roller

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