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# *THE* **POLIO** **SOCIETY**

## **AN INTRODUCTION**

*There is a unique bond among polio survivors – the shared experience of having fought back, triumphed and endured. Now the strength and determination that you put into fighting polio decades ago can once again be used to ensure your future and the future of your fellow polio survivor.*

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## **Background: *The Need***

Throughout the first half of the twentieth century, polio received considerable attention from the mass media and the medical and research communities. Because polio tragically affected hundreds of thousands of individuals and families, vast financial resources were committed to seeking effective treatments and a lasting solution. The March of Dimes Foundation was created exclusively as a national public fund-raising organization to help scientists discover a safe vaccine and to provide medical and rehabilitation equipment and support services to polio survivors and their families.

With the development of the Salk (1955) and Sabin (1961) vaccines, polio became, to a large extent, a conquered disease in the United States. The March of Dimes turned its attention and resources away from polio, focusing instead on birth defects and maintaining only limited financial support for people who had survived polio with severe respiratory impairments. Since the 1960s, polio survivors have been on their own, and most have successfully made their way into society's mainstream.

Yet while polio is one of the great success stories of the century, it is not a closed book – and it has an unfortunate epilogue.

During the late 1970s, polio survivors overwhelmingly began to seek medical advice for a new set of functional health problems. These new problems included joint and muscle pain; muscle weakness; fatigue; sleep, breathing and swallowing disturbances; and an increased sensitivity of cold. Now known as the late effects of polio or, more commonly, post-polio syndrome, these symptoms were initially little understood by the medical community or the public at large. Some professionals believed that the new symptoms were a result of an accelerated aging process related to polio, or simply due to the natural effects of aging. Others blindly attributed an individual's new functional health problems to psychological difficulties.

In response to the lack of support from the medical community and the general public, a national grass-roots movement emerged during the mid-1980s to help address the new problems facing polio survivors. In 1981, the Gazette International Networking Institute (G.I.N.I.), now known as Post-Polio Health, organized the first consumer conference on the late effects of polio, inviting key representatives from the physical medicine and rehabilitation world. Since then, polio survivors, working together, have been instrumental in helping to establish polio clinics and support groups throughout the country. Their persistence has forced the medical community to become more better informed about the new health problems facing polio survivors, thus helping to eliminate the dismissal, misdiagnosis, and mistreatment too often encountered by those seeking medical assistance.

In 1982, a group of Washington, D.C. Area polio survivors began to meet regularly to share their concerns about the lack of public awareness of and national attention to the the late effects of polio, as well as the lack of research being conducted on post-polio's cause (s) and treatment(s). Formally established in 1984 as the Post-Polio League for Information and Outreach, The Polio Society as it is now known, is dedicated to delivering state-of-the-art medical and other health-related information to the polio community, their families and friends, and the health care professionals who serve them. Begun by polio survivors for polio survivors, the Society is committed to being a voice for the over 650,000 individuals who live with the after effects of polio today.

### **The Polio Society: *Our Mission***

The Polio Society was created for the purpose of providing educational resources and support group services to people who had polio and are now experiencing the late effects of polio. We are a chartered non-profit 501C(3) organization governed by a board of directors composed primarily of polio survivors and family members of polio survivors. Our programs and services are funded by membership dues, gifts and private contributions. Because we are staffed chiefly by volunteers, with limited part-time administrative assistance, our overhead expenses are remarkably low --- virtually every

penny of our donations goes toward programming and outreach efforts.

**The Polio Society's achievements include:**

- ● *maintaining a national membership of 4,500 polio survivors and health care professional, and continually seeking to increase awareness in the polio community through local and nationwide efforts;*
- ● *sponsoring and coordinating major national UPDATE conferences about post-polio issues. Five conferences have been held since 1985, attracting nearly 1,500 participants and reaching hundreds more through video and audio tapes of the sessions;*
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- ● *publishing OPTIONS, a quarterly newsletter of current medical research, available resources, support activities and first-hand accounts from the polio community;*
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- ● *sponsoring monthly information and support group meetings in the D.C. Metropolitan area, and providing technical assistance and guidance to support groups throughout the U.S.;*
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- ● *providing access to state-of-the-art medical and psychosocial information about the late effects of polio, including audio and video tapes of conference presentations, current scientific and lay articles, and polio-related publications;*
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- ● *sending informations packets on the late effects pf polio to over 1,000 individuals and organizations each year;*
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- ● *promoting public awareness through poster campaigns, local and national newspapers, and network television and radio;*
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- ● *educating and addressing Congress about the need for federal funds for post-polio research and supporting legislation that promotes access for people with disabilities.*

Many polio survivors are now facing difficult choices about work, family life and daily activities ... indeed, about their very independence. Information to assist you in making healthy choices is available. The Polio Society, through its resources and programs, can provide options.

**Polio Society Member Benefits**

- ● *OPTIONS, our quarterly newsletter, which provides useful information and valuable advice on coping with the late effects of polio;*

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- ● discounts on conference fees, educational materials, and polio-related publications;
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- ● reprints of scientific articles sent to your physician(s) upon request;
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- ● support of The Polio Society's leadership role in educating Congress about the need for research support from the National Institutes of Health and the Centers for Disease Control;
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- ● pride in the knowledge that you are helping yourself and others toward a common goal.

Please call (301)879-8180 for a membership form, or send your tax-deductible donation of \$25.00 (individual) or \$50.00 (institutional) membership to ***The Polio Society, 4200 Wisconsin Avenue, N.W., Suite 106273, Washington, D.C. 20016.***

#### **Additional Post-Polio and Disability Resources**

- ● For disability-related information, contact your local Independent Living Center. The Independent Living Research Utilization Research and Training Center (2323 S. Shepherd, Suite 1000, Houston, Texas 77019; 713-520-0232) publishes a National Directory of Independent Living Centers and Related Organizations.
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- ● For additional information about post-polio health issues, contact Post Polio Health (5100 Oakland Avenue, #206, St. Louis, MO; 314-534-0475).
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- ● For information about swimming facilities with heated pools and/or programs designed for people with muscle and joint pain, contact your local chapter of the Arthritis Foundation.

Thank you for your request for information. Feel free to call 301-897-8180 if you have any questions.