

Telling Stories

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Polio Stories Featured on PBS ...

KERA Dallas/Fort Worth is presenting a co-production of Texas Scottish Rite Hospital for Children and Ken Mandel Productions, "A Fight to the Finish: Stories of Polio."

Check your local listing or schedule at www.kera.org/tv/productions/fight.

notes, bibliography, index and post-polio resources in Canada.

The personal stories are arranged chronologically based on the year of onset (1924-1984). Doing so gives a small glimpse of the succession of

limited treatments used to treat acute poliomyelitis. The stories, as edited, feel honest, conveying the sense that this *is* their story and their analysis (although limited) and not the story they *think* is the typical polio story.



Editors of *Walking Fingers*: (left to right) Helen D'Orazio, Sally Aitken and Stewart Valin, members of Polio Québec (www.polioquebec.org/fr), a group founded in 1984.

Story after story lauds the contributions of Neil Cashman, MD, and Daria A. Trojan, MD, physicians at the Montréal Neurological Institute and Hospital. (Cashman is now in Toronto and Diane Diorio, MD, a neurologist, is working with Dr. Trojan.) Many of the survivors have accepted the wisdom of respecting and working with a knowledgeable physician, while educating and proactively helping themselves.

Dr. Trojan contributed the concise chapter about post-polio syndrome. Other chapters include a history of polio in Canada and the Canadian vaccine story which involves Paul Martin, Sr., the father of the current prime minister. Both father and son had polio, and the book contains an interview by the editors with Paul, Jr., although it is attributed erroneously to another.

Parts Three and Four provide the points of view of health professionals and family members. "Maybe My Dad

Didn't Go to War, but He Fought One of the Great Battles of the Century" is editor Stewart Valin's heartfelt tribute to his father and the story from which the book title was extracted. The post-polio literature is lacking in stories written by others involved in our polio history and these small sections attempt to correct this.

Editor Helen D'Orazio contributed the chapter about Sister Kenny and her story — "I Am More Than My Polio" — as a polio survivor whose arm was affected and who lived in a family where polio was never discussed.

The impetus for *Walking Fingers* was *Histoire vécu de la Polio Québec* published in 2000 by Carte Blanche and sold by Polio Québec (www.polioquebec.org/fr/livre.html). Polio survivor Sally Aitken, whose story is not included, was the force behind both books as she served as visionary, interviewer and editor. Aitken's personal polio experience, '60s individualist spirit, years of involvement in post-polio advocacy, willingness to allow others to have a voice, and her recent battles with benign brain tumors uniquely qualified her to initiate and complete the project. ●

Walking Fingers: The Story of Polio and Those Who Lived It (ISBN-1-55065-180-3) is an excellent addition to the literature documenting Canada's polio past. Copies may be ordered by your local bookstore for US \$18.95/CAN \$24.95 or at www.vehiculepress.com.

Post-Polio Breathing and Sleep Problems Revisited

Judith R. Fischer, MSLS, Editor, *Ventilator-Assisted Living*, and Joan L. Headley, MS, Editor, *Post-Polio Health*

“Post-Polio Breathing and Sleep Problems” was published in the fall of 1995 (*Polio Network News*, Vol. 11, No. 4). As a result of the continual flow of phone calls and emails from polio survivors and family members about this life and death topic, Judith Fischer, editor of *Ventilator-Assisted Living* (our other quarterly newsletter), and I decided to revisit and revise the original article. Our goal is to educate and to clarify misinformation about breathing problems of polio survivors. —Joan L. Headley, Editor, *Post-Polio Health* (ventinfo@post-polio.org)

New breathing and sleep problems in aging polio survivors can be insidious and often go unrecognized by either polio survivors, their family members or their health care providers. Polio survivors may have weakened breathing muscles as a result of the initial damage by the poliovirus; the lungs themselves were not affected. Those who were in an iron lung during the acute phase should be aware of the potential for developing problems later in life and educate themselves in order to recognize important signs and symptoms which may indicate underventilation which may lead to respiratory failure. Even those who did not need ventilatory assistance during the acute phase may also be at risk for underventilation and should be aware of problems with breathing and sleep.

Underventilation (hypoventilation is the medical term) means that not enough air reaches the lungs to fully inflate them. The result may be too little oxygen and too much carbon dioxide (CO₂) in the blood. Under-ventilation can be caused by one or more of the following: weakness of the inspiratory muscles (mainly the diaphragm and rib muscles) for breathing in, weakness of the expiratory muscles (the abdomen) for breathing out and producing an effective cough

to clear secretions, scoliosis (curvature of the spine), and sleep apnea.

Other factors contributing to a polio survivor's breathing problems are a history of smoking, obesity, undernutrition, and other lung diseases such as asthma, bronchitis and emphysema.

Vital capacity (VC) is the volume of air that can be expelled after taking a big breath and is a measure of how well the lungs inflate. VC normally decreases with age, but this decrease in VC is more serious in an aging polio survivor with weakened breathing muscles. Many polio survivors had impairment of their inspiratory muscles, and the normal changes due to aging may cause them to lose VC at a greater rate. Polio survivors may not experience symptoms of underventilation until their VC falls to 50% or less of predicted (normal).

Signs and symptoms of under-ventilation during sleep include:

- ◆ inability to breathe when lying flat — the need to sleep sitting up (orthopnea)
- ◆ inability to fall asleep and/or to stay asleep (insomnia)
- ◆ anxiety about going to sleep
- ◆ restless fragmented sleep with frequent awakenings

Thanks to Lisa Krivickas, MD, Spaulding Rehabilitation Hospital, Boston, Massachusetts; E.A. Oppenheimer, MD (retired), Los Angeles, California; and Mark H. Sanders, MD, University of Pittsburgh Medical Center, Montefiore University Hospital, Pittsburgh, Pennsylvania, for their reviews of this article.

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