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Polio Echoes...

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Book MS – Contents – Zoom in on Part X, “Polio Echoes”

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Jane Atkey has Post-Polio Syndrome (PPS) – a little known ailment that creeps up on its victims like a vindictive ghost, striking them 25 to 45 years after they first did battle with polio. These are people who lost

precious years of their lives to a horrifying scourge, who spent countless hours in therapy to rehabilitate crippled limbs or lungs, people who thought they had recovered completely, who threw away crutches and canes and refused to consider themselves among the disabled. No one warned them that polio could come back to haunt them.

“Polio Again?” *Homemaker’s*, Summer 1996

While the global eradication of the wild poliovirus inevitably approaches, the personal, social and political effects of the debilitating disease it caused continue to echo across Canada.

Though increasingly forgotten by most parents, the occasional mention of polio in the popular media continues to pack a potent emotional and political punch. This potency has been apparent when, for example, an imported or a vaccine-associated polio case is reported, or a shortage of vaccine prompts a public debate about the relative merits of Salk vs. Sabin.

An almost instinctive understanding of what polio meant, and what it could mean for want of either vaccine, has persisted not far beneath the skin of most Canadians, especially middle-class parents with young children.

However, for the 50,000 Canadians who fell victim to polio during the pre-vaccine era, or after, the echoes of polio have been increasingly loud, personal and devastating. Many have found themselves faced with the debilitating effects

of polio again due to what has become known as post-polio syndrome.

The personal, medical and political challenges of post-polio syndrome have sparked a remarkable mobilization of organizational energy across Canada reminiscent of the March of Dimes' campaigns of the epidemic era. Indeed, in Canada, the primary organizational force in support of the post-polio syndrome community has been the Ontario March of Dimes.

Today, I'd like to trace the story of how polio has continued to echo, particularly in Canada, focusing on the 4-5 decades since polio vaccines ended the epidemics...

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In August 1978, *Maclean's* magazine described Canada's last polio scare as a "Flashback to a Nightmare." That summer, 11 paralytic polio cases struck members — mostly adults, all of whom were unvaccinated — of the Netherlands Reformed Church in Alberta, British Columbia and Ontario.

This polio scare sparked a 'crazy binge' for Salk vaccine shots in Toronto emergency immunization clinics after 2 polio cases and another 2 suspected cases were reported in southwestern Ontario. Two cases also appeared in Alberta and B.C., and pressures built on provincial health ministries there to set up emergency clinics. If the situation continued, polio vaccine shortages were expected.

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By August 11th, 80 people were under quarantine in the southwestern Ontario town of Norwich, with “the list growing by the minute,” according to the Oxford County Medical Officer of Health. The Norwich doctor who reported the first case in the outbreak told the *Toronto Star* that “This is the most serious thing I’ve run across in my 26 years of practice. Don’t call the situation critical, but you can certainly call it severe.”

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A few days later, the *Toronto Star* published a full-page feature story on the history of polio in Ontario titled, “They Beat Polio – Recurring Nightmare,” which highlighted the personal polio stories of several local luminaries. While most of the article discussed the polio epidemics of the 1930s, the article began by focusing on show-business entrepreneur, Garth Drabinsky and musician Doug Riley, both of whom had contracted paralytic polio at age three. Like other celebrities who had polio, Drabinsky said “he overcame the mystery killer and never looked back.” Nevertheless, the *Star* reported, while Drabinsky and Riley “rarely think of their bouts with polio anymore and only have minor disabilities, they both say that the current threat ““petrifies them.””

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On November 21, 1978, the *Edmonton Journal* captured the Alberta situation with the headline, “Polio Scare Brought Back the Worries of the ‘50s.” The article highlighted Alberta’s polio experience during the epidemic era, noting “[t]he heart-breaking accounts of the polio epidemics of 20, 30 and even 40 years ago jam *Journal* files, and paint a picture of mass fear that was repeated on a smaller scale with the diagnosis of one case of polio near Lethbridge.”

While Manitoba was spared the 1978 polio scare, its timing coincided with the 25th anniversary of the great 1953 epidemic that swept the province and most of the country. The *Winnipeg Tribune* of November 21, 1978 published a feature article, “The 20 Who Can’t Forget the 1953 Polio Epidemic,” which recounted the stories of several polio survivors who had remained on a second-floor ward of Winnipeg’s King George Hospital since the epidemic. Most of these survivors continued to be dependent on iron lungs and/or other types of respiratory support equipment. “Some people can’t bear to see them,” the article began. “They find the encounter too painful, too upsetting. Others weep. It’s not an easy reality to confront, an even harder one to have to live day to day.”

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All but forgotten for 25 years, survivors of the great Manitoba polio epidemics of 1952 and 1953 received attention when they became the focus of a pioneering follow-up study in 1979-80. As its principal author, Joseph M. Kaufert, of the

University of Manitoba's Department of Community Health Sciences, recalled, this study was prompted by the decision of Rehabilitation International, a global federation dedicated to protecting the rights of people with disabilities, to hold its 1980 Congress in Winnipeg.

Dr. Kaufert is joining us today.

Drs. J.A. Hildes and A.J.W. Alcock, who had worked at ground zero in Winnipeg's King George Hospital during the 1952 and 1953 polio epidemics, suggested conducting a follow-up study to be presented at the conference. The Manitoba Ministry of Health provided a small grant, and Joseph Kaufert and his wife Patricia were brought in to develop a questionnaire and conduct interviews with post-polio patients.

The study resulted in a series of papers delivered at the Rehabilitation International conference held in Winnipeg in June 1980, and then published in the *University of Manitoba Medical Journal*. The subjects were 186 polio cases involving patients who had initially required respiratory support and had survived for three months or more. When the study began, about 150 of the patients had not been seen at King George Hospital for many years. However, all but 13 of these were tracked down, and all but two agreed to be interviewed. The main study, entitled "The Physical and Social Consequences and Rehabilitation of Respiratory Polio," differentiated the severity of the cases, tracking such factors as current activities and respiratory status, major health problems, employment

experience and family events. The study did not mention reports of individuals encountering a return or a worsening of their particular polio symptoms after a period of recovery and stability, a condition that would later be described as post-polio syndrome.

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At about the same time as the Manitoba follow-study began, reports were emerging in the United States suggesting that some polio survivors were experiencing worsening polio-like symptoms as they aged. A letter from a 57-year-old polio survivor, Larry Schneider, from Tucson, Arizona, published in the *Rehabilitation Gazette* in 1979, proved very influential. Schneider contracted paralytic polio at age 17 and wrote that over the previous few years, “I find myself being able to do less and less and tire too easily.” Most frustrating for Schneider had been the lack of support from doctors. “To each doctor, I was a strange and different individual because he was totally unfamiliar with polio. They were all more interested in learning from me than giving me any worthwhile information. Most of them looked at me and said I would be a good ad for polio shots.”

Schneider’s letter, coupled with the 25th anniversary of the Salk vaccine, attracted the attention of NBC television in 1979-80. The network produced a news item for its *Prime-Time Saturday* program that focused on Roosevelt Warm

Springs Institute for Rehabilitation in Georgia. Franklin D. Roosevelt had rescued Warm Springs in 1927, after which it developed into a major rehabilitation centre for polio patients during the epidemic era. Schneider had been able to go to Warm Springs whenever he had a problem or question related to his polio, but he discovered recently that “with the switch in the March of Dimes, this is no longer true.”

Beginning in 1958, the National Foundation for Infantile Paralysis/ US March of Dimes had begun to shift its focus to the challenge of preventing and treating birth defects. By the late 1970s, the March of Dimes no longer directly supported Warm Springs, or any of the other polio rehabilitation centres it had established around the United States. However, sparked by the NBC news report, many polio survivors in the U.S. began desperately to seek assistance from the former polio rehabilitation centres. Similar interest was sparked among polio survivors in Canada who had seen the NBC report. But they discovered both limited services and a lack of awareness or understanding on the part of the Canadian medical community of such late-effects of polio.

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Prompted by the new media attention and the declaration from the United Nations that 1981 would be the International Year of the Disabled, Gini Laurie, founder of the journal that had published Schneider’s letter, decided to act. With the support

of the Rehabilitation Institute of Chicago, Care for Life and the National Foundation/ March of Dimes, a landmark international symposium entitled “Whatever Happened to the Polio Patient?” was held in Chicago in mid-October 1981. Some 200 participants from a variety of countries attended.

As Kaufert recalled, the Chicago meeting was a “reconnection for the generation of physicians and other health professionals who had done the heroic work in both acute care rehabilitation and public health.... [it] was like a reunion of former professionals and former patients – all of whom wanted to know what the late effects meant.” Audrey King, who contracted respiratory polio in England in 1952 before moving to Canada, played a prominent role at the conference.

King’s presentation highlighted what she had been able to quickly gather about the Canadian polio experience during the 1950s, particularly in Ontario, as well as the rehabilitation services available. Her main focus was the current polio situation in the province. “Agencies originally set up to meet the needs of polio patients now incorporate all physical disabilities, in much the same way that the polio vaccine itself is now included with vaccination against other childhood illnesses.” There was thus little knowledge about the special problems polio survivors now faced. “Because of this integration, the unique problems faced by people with polio have become minimized over the years and not given the importance that I think is now required.” Unlike in Manitoba, it seemed to King that “[p]erhaps there were too few of us in Ontario, particularly those of us who

use respirators.” It was uncertain how many survivors there were and where they might be in the province. “I sometimes have wished the epidemics had been larger so that we would feel less neglected in Ontario.”

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The Chicago conference sparked considerable media attention. Audrey King was the main focus of a *Globe and Mail* article in late November 1981, titled “Polio Survivors: Victims of Epidemic Feel Old, Abandoned.” Nancy Skinner, another “old polio” survivor was also profiled. “These women are not complainers, far from it,” the article noted. “They’re bright, intelligent women who have lived a life-time with their disability and have succeeded.” However, as Skinner stressed, “we have to prove ourselves all the time. It was drummed into our heads in rehabilitation to be independent in all modes of living.”

King pointed out that immediately following the 1980 NBC broadcast, “doctors were swamped with phone calls. Studies were suggested. People were writing back to the original polio centers like Warm Springs, Georgia, and the Sister Kenny Institute. They were saying that as soon as the vaccine was out, we were abandoned. No more polio. No more us.” King suggested that a Canadian conference for polio survivors should be held, sponsored by the Ontario March of Dimes or another such agency. Andria Spindel, Executive Director of the Ontario March of Dimes, felt that “there has been a ‘resurrection’ of polio survivor

problems and now people are looking at creating a study on the issue.”

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Among the studies launched after the Chicago conference was a 1982-83 expansion of the original 1980 Manitoba follow-up study, which included about 800 of the provinces’ original 3,645 polio victims stricken between 1950 and 1959. Funded by a federal grant and headed by Kaufert, this larger follow-up study focused on polio survivors who had been admitted to hospital. It hoped to determine whether people handicapped with polio had aged differently than, as described in a *Winnipeg Free Press* report, “those who were blessed with more normal medical histories.”

By early 1983, Kaufert’s study was able to examine 530 polio survivors from across Manitoba, 90% of whom had recovered enough to lead productive lives. However, Kaufert recognized that because many of the polio victims of the 1950s were now middle-aged, their needs were changing. John Alcock, who worked with Kaufert on the study, noted that “Parents and spouses or other relatives may be too old to help as they once did.” It was important to identify the aging problems that were unique to polio victims so that provisions could be made for their future care. As Kaufert suggested in a *Maclean’s* article, “Rather than re-hospitalizing a lot of people when their families become too old to help them, we should be planning ahead, perhaps for more residences for the polio-

handicapped, or for any other large group of handicapped people, such as those disabled in wars.”

In the meantime, the Ontario March of Dimes, energized by King and Skinner’s recommendations after the Chicago conference, organized a one-day post-polio workshop held on April 22, 1983 in Willowdale, Ontario. Seventy-nine people attended, 48 of whom had been disabled by polio. At the end of the day, the Ontario March of Dimes made several commitments to polio survivors. They included notifying workshop participants about their services, preparing an Ontario Registry of those affected by post-polio syndrome and preparing a questionnaire for post-polio physicians to assess their areas of concern for future research.

The Ontario March of Dimes quickly focused on fulfilling the commitments made during the workshop, including establishing a Post-Polio Committee and submitting a grant application to Health and Welfare Canada for research into the needs of Ontario residents affected by post-polio syndrome.

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During the summer of 1983, the 30th anniversary of the 1953 polio epidemic prompted the Canadian press to once again bring the terror of the devastating “summer plague” before the public.

The main focus of media attention was on Manitoba’s polio experience,

highlighting how the 1953 epidemic had scarred a generation, creating a large group of disabled people who would become founders of advocacy lobbies for the disabled, and spurring great advances in medical technology. As was the case in 1978, newspaper and magazine articles focused on the polio patients still resident in King George Hospital.

Press attention in 1983 also highlighted twelve polio patients who still resided at Pearson Hospital in Vancouver, as part of an article entitled “Vaccination still fought by some.” This article recalled the 1978 polio scare that jolted British Columbia back into the reality of polio. However, the press attention sparked by the 30th anniversary did not mention the new physical challenges faced by many polio survivors.

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Through 1984, the Ontario March of Dimes Post-Polio Committee intensified its work, supported by a Health and Welfare Canada grant of \$40,000 over two years. A coordinator was hired to organize a network of local post-polio support groups around the province, beginning in Ottawa in October 1984.

The Committee also focused on building a provincial post-polio registry, meeting with physicians and therapists to discuss the needs of post-polio patients. The Ontario March of Dimes’ leading role in this issue attracted inquiries about the late effects of polio from Kuwait, the United Arab Republics, as well as

individual polio survivors from across Ontario, other provinces and the U.S.

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In the fall of 1984, broader public awareness of the personal impact of polio emerged when well-known writer, Scott Young, published a dual biography entitled *Neil and Me*. The book included a chapter that described the dramatic story of 5-year-old Neil Young suddenly contracting polio over the Labour Day weekend of 1951. He was rushed 90 miles through a thunderstorm in the back of the family station wagon, wearing a surgical mask and clutching a new toy train. Scott Young first wrote down the story of his youngest son's polio experience shortly after Neil returned home in early September 1951 to recover, but he kept the manuscript in a filing cabinet for more than 30 years.

In mid-October 1984, the *Globe and Mail* published extracts from *Neil and Me*, the first section of which recounted Neil's polio experience. "You have to be a certain age to remember the polio epidemic in the late summer of 1951, before there was a Salk vaccine to control the disease," the extract began. Scott Young's recounting of Neil's polio story would have an impact on young Canadian fans who had likely never heard of the disease.

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I was one of those fans. I was born in 1962, the same year OPV was introduced,

and grew up with no direct experience of this disease. Neil's polio story was the inspiration for a research journey leading from my undergraduate years to this presentation.

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Through 1985, the Ontario March of Dimes pressed ahead with considerable intensity developing its post-polio program. The program focused particularly on completing a Post-Polio Registry and questionnaire, facilitating the establishment of local post-polio support groups and hosting the Ontario March of Dimes' Roosevelt Post-Polio Seminar held at Lyndhurst Hospital in Toronto on June 1, 1985.

Audrey King, now Chair of the Ontario March of Dimes' Post-Polio Committee, addressed the Toronto seminar, outlining the Ontario post-polio program to the 180 attendees. Emphasizing the importance of the media attention given to the late effects of polio since the 1980 NBC report, she noted how North American media coverage of the post-polio situation had expanded. Indeed, the "resurrection" of polio and the awareness of post-polio syndrome was very much shaped by media attention, particularly through the mid-1980s.

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For example, south of the border, ABC television's *Nightline* focused on the

“medical mystery” of the late effects of polio in 1985. The *Nightline* segment featured a discussion about post-polio syndrome with Dr. Albert Sabin and Dr. Richard L. Bruno. Dr. Bruno, a clinical psychophysiologicalist at Columbia-Presbyterian University in New York City, had recently begun neurological studies into the late effects of polio. As Bruno later recalled in his comprehensive book, *The Polio Paradox: Understanding and Treating Post-Polio Syndrome and Chronic Fatigue*, “the media started to get wind of our research.”

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Fueled by new Canadian media interest, such as a seven-minute segment on post-polio syndrome that aired on CBC television's *The Journal* in March 1986, Canadian post-polio organizational work continued to develop in Ontario. In particular, new local post-polio support groups were launched in Kitchener/Waterloo, London, Oshawa, Barrie, Peterborough, Gray-Bruce-Huron, St. Catherines-Niagara, Timmins-Kirkland Lake, Thunder Bay, Sault Ste. Marie and York Region. Following a pilot study, the West Park Hospital Post-Polio Clinic in Toronto officially opened in the fall of 1986.

In the meantime, organizational and educational efforts also spread beyond Ontario to other parts of the country. In May 1986, King was the keynote speaker at the 2nd Alberta Post-Polio Conference in Edmonton, which was hosted by the Northern Alberta Post Polio Support Group. Further west, the Post Polio

Awareness and Support Society of British Columbia was formed in 1986. The Society worked closely with the Kinsmen Rehabilitation Foundation of B.C., which traced its interest in the polio problem to the mid-1940s.

In Manitoba, the Post-Polio Network (Manitoba) Inc. was formally established in February 1986, linking its roots to an earlier self-help group, the “Polio Optimists” that had formed after the major epidemics of the early 1950s. The Polio Optimists remained active until the mid-1960s, when the group donated its residual funds to the Canadian Paraplegic Association. By the early 1980s, polio survivors active in cross-disability organizations felt a need to create a new self-help group focused on the late effects of polio. The Canadian Paraplegic Association, the Society for Manitobans with Disabilities and a local radio station provided support for the initial organization of the new Post-Polio Network.

To the east, Polio Quebec was established in August 1985 by two polio survivors, Seiglinda Steida and Mona Aresenault, who were frustrated by the lack of medical help and agency support available in the province. However, by December 1986 another organization, the Quebec Post-Polio Association, displaced the first group, with Aresenault later assuming the presidency. The Quebec Post-Polio Association was officially incorporated with a 14-member Board of Directors, various committees and a medical advisor, Dr. Neil Cashman, who opened a Post-Polio Clinic at the Montreal Neurological Institute in 1987.

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By early November 1986, when the Ontario March of Dimes hosted its first province-wide post-polio conference in Toronto, the Post-Polio Registry had grown to include 1,800 names. Its growth, as noted by Shirley Teolis, coordinator of the Ontario March of Dimes' Post-Polio Program, was fueled by "a lot of media attention."

For example, the November 3, 1986 edition of *Maclean's* contained an article, "Echoes of an Epidemic," that focused on the soon-to-be-opened West Park Post-Polio Clinic. According to Dr. Roger Goldstein, West Park Hospital's director of respiratory medicine, the new clinic was "the first of its kind in Canada," and he hoped "to shed some light on this syndrome." Goldstein referred to the "post-polio syndrome," the term increasingly used to describe the late effects of polio.

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In January 1987, the Ontario March of Dimes announced that its honorary chairman for its annual fundraising campaign would be Paul Martin, Sr., now 83 years of age. The headline in the *Toronto Star* underscored that "Former health minister cites childhood polio for personal effort."

Paul Martin, Sr. was born in 1903 and developed paralytic polio in 1907, while Paul, Jr. was struck by polio in 1946. For Martin, Sr., the 1953 polio

epidemic was the worst that Canada had ever faced and, as Minister of National Health and Welfare, he was in the middle of it. “It was a shock but also an inspiration and a spurring on to do something,” he recalled, referring to his key role during the 1953 epidemic and the subsequent introduction of the Salk vaccine.

Martin, Sr. stressed how polio had a very personal meaning. He had borne “its scars into adult life – slightly deformed knees and a partly paralyzed upper body.” He said, “I was bedridden for four years. I was on a wagon and had to be driven around... Many died. I was one of the lucky ones.” So, too, was Paul Martin, Jr, who in 1987 was president of Canada Steamship Lines. According to his father, Paul, Jr. “shook off polio with no lasting effects.”

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Paul Martin, Sr.’s appointment as honorary chairman of the Ontario March of Dimes was coincident with the 50th anniversary of the 1937 Ontario epidemic, which hit Toronto hard. “The Plague of ‘37”” was the *Toronto Star* headline on September 6, 1987, its tagline highlighting how “When polio hit Toronto schools stayed closed and 758 lives changed forever.”

This article, unlike the press attention focused on the 30th anniversary of the 1953 epidemic, included discussion about the growing problem of post-polio syndrome. An estimated 5,000 polio survivors lived in Ontario, the article noted,

“...and today as many as one in five may see, 25 to 30 years later, the emergence of what’s called post-polio syndrome.” The Ontario March of Dimes had registered 365 polio survivors in Toronto by 1987 and had facilitated the creation of 16 polio survivor support groups across the province.

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By November 1988, when the Ontario March of Dimes hosted the first national Conference on the Late Effects of Polio in Toronto, provincial post-polio organizations had been started, or were in the process of being formed, across Canada, except in Nova Scotia and Prince Edward Island. A post-polio support group in New Brunswick was started in 1987, and in Newfoundland, a small post-polio group was started in 1988 after a polio survivor, Mel Fitzgerald, who had attended several post-polio seminars in Canada and the U.S., attracted 18 other polio survivors to a first meeting in St. John’s by placing a newspaper ad.

The first meeting of the Calgary-based Post-Polio Association of Southern Alberta was held on February 1, 1988, spurred on by the absence of post-polio information and resources in that part of the province. A small group of six Calgary polio survivors, led by Remy Houghton, informed reporters at the *Calgary Herald* about a meeting they were planning in January 1988. The resulting half-page article helped attract 168 people to the first meeting.

At about the same time in Saskatoon, Sibil Bock was experiencing several

problems associated with the late effects of polio. After extensive reading and discussions with a small group of 19 fellow polio survivors with similar problems, she started a post-polio support group that officially became the Saskatchewan Awareness of Post-Polio Society Inc. in 1989.

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Among the delegates to the Ontario March of Dimes' first National Conference on the Late Effects of Polio in Toronto, were Audrey King, Gini Laurie, and Joseph Kaufert, each of whom gave a presentation. The common theme was assessing the personal, organizational and networking progress made in response to post-polio syndrome since the 1981 Chicago conference.

Kaufert's presentation highlighted the connections between the epidemic and post-polio eras in Canada. He concluded his presentation by showing a timeline that underscored the changes in voluntary organizations, stressing that "[t]he history of post-polio experience in Canada and North America is really a history of individual advocacy and personal networks." For example, when Kaufert first met Audrey King in 1981, through Gini Laurie, "there was suddenly a connection between people in Manitoba and people in Ontario that were at least thinking and worried about the late effects."

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A few months before the Late Effects of Polio Conference, in July 1988, a nine-month-old baby was diagnosed with polio in the east Toronto suburb of Scarborough. This was the first laboratory-confirmed polio case in Ontario since 1979. The baby had already received three doses of Salk vaccine.

The case was made public in mid-January 1989, the *Globe and Mail* reporting that there was nothing wrong with the vaccine. Rather, it seemed that the baby did not respond to the vaccine. According to Connaught Laboratories' associate medical director, Dr. Luis Barreto, about 2% of the population did not experience a strong enough immune reaction to the vaccine to adequately protect against the disease. The baby most likely was exposed to the wild poliovirus from family members or visitors who had recently returned from the East Indies, where the wild poliovirus remained endemic. This case underscored one of the major reasons behind the polio eradication effort, which launched in 1988. In a context of rapid international air travel, Canada and other essentially polio-free countries were vulnerable to importations of the wild poliovirus from endemic countries.

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Amidst increasing North American media attention to the global polio eradication program, an Ontario shortage of Salk vaccine reawakened the Salk vs. Sabin issue, and more immediately, led to delays in adult booster shots. By November 1989, unexpected production delays in Connaught Laboratories' efforts to

introduce a new generation of enhanced potency Salk vaccine, resulted in an estimated two-year shortage of the inactivated vaccine in Ontario, particularly in the combined diphtheria-pertussis-tetanus-polio (DPT-Polio) form, of which the province required 840,000 doses each year.

Ontario's Chief Medical Officer of Health, Dr. Richard Schabas, suggested that the province would switch to the Sabin oral polio vaccine, Connaught's public affairs director explained the IPV shortage by noting, "Our product is not like Aspirin®. It takes a long time to manufacture and we have to wait for approval on everything that's being released."

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Two years after the Ontario vaccine shortage, two significant polio and post-polio anniversaries took place in Canada. In January 1991, the Ontario March of Dimes marked its 40th anniversary. The *Hamilton Spectator* highlighted the work of the "Marching Mothers," and in particular, Ellen Fairclough, then 85, a former Hamilton Member of Parliament and the first woman appointed to a federal cabinet. Driven by her own son's encounter with paralytic polio in 1947 at age 16, Fairclough served on the board of directors of the Ontario March of Dimes, often leading groups of Marching Mothers around Hamilton neighborhoods during the fundraising campaigns of the 1950s. By the 1991 campaign, the Ontario March of Dimes no longer canvassed from door to door as the Marching Mothers had, but

nevertheless, hoped to raise at least \$90,000 in the Hamilton region.

Not publicly celebrated, but similarly significant to the support of polio survivors, was the 10th anniversary of the 1981 international Chicago post-polio conference. In their 1991 report, *Profile of Post-Polio Networks and Self-Help Groups in Canada*, Joseph Kaufert, along with George M. Torrance of Social Research and Consulting, concluded, “All things considered, the Canadian post-polio movement must be seen as a remarkable achievement in self-help over a decade.” In particular, the report emphasized, “A substantial amount of media publicity has been generated and it is probable that most Canadians now have at least heard the terms ‘late effects of polio’ and ‘post-polio syndrome.’”

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More post-polio conferences followed in 1992, among them the Ontario March of Dimes’ Destination ’92: Well-Being for Polio Survivors. Held in Mississauga in mid-June, the conference was tailored “for people who had polio, their families, friends and health care professionals.” In October 1992, an international post-polio conference took place in Richmond, British Columbia. The media focused on the story of its organizer, University of Victoria president, Howard Fetch, who contracted polio in 1925. “Now 67, Fetch had been overcome by a crushing fatigue that no amount of sleep could overcome.” Faced with post-polio syndrome, “I gradually – through being very, very careful – got my energy back

and got through the period.”

By 1992, with provincial and local organizations dedicated to supporting polio survivors established in all regions and most provinces of Canada, the focus of development and activity shifted to the national level. For example, a Steering Committee meeting of a National Polio Network assembled in Mississauga in late October 1992. Key objectives included providing a bilingual clearinghouse of information on post-polio syndrome, assisting provincial associations, encouraging research into post-polio syndrome and fostering “public awareness of post-polio syndrome on a national basis.”

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During the early-to-mid-1990s, the echoes of polio intensified in Canada and the media interest fell upon post-polio syndrome issues. The 40th anniversary of the great 1953 polio epidemic followed by the 40th anniversary of the Salk vaccine provided the catalyst. During this period, my own research into the history of polio in Canada began to be disseminated, contributing to greater media interest in polio in Canada.

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In 1993, CBC Television’s *Prime Time News* produced a 25-minute *Magazine* feature documentary entitled “Conquering the Crippler.” The film focused on the

1953 Manitoba epidemic, telling the story of Canada's and Connaught Laboratories' essential contributions to the development of the Salk vaccine. I was hired as a research consultant for this project, gaining access to Connaught's archives and helping facilitate timely interviews, especially with Jonas Salk and Nell Martin, widow of Paul Martin Sr., who died shortly after the interview. The interview was also one of Salk's last, as he died in June 1995. "Conquering the Crippler" first aired in December 1993 and proved to be a model for subsequent Canadian TV documentaries on the history of polio.

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Spring 1995 marked an important milestone in the history of polio in Canada, the 40th anniversary of the introduction of the Salk vaccine. Among the many events leading up to the official April 12 anniversary, a special breakfast reception was held on Parliament Hill in Ottawa on April 5th sponsored by the Southern Alberta Post Polio Association (SAPPS). Spearheaded in Ottawa by Jan Brown, a Reform Party MP with a keen interest in post-polio issues, the event was held to honour Jonas Salk, Connaught Laboratories and Paul Martin, Sr. for their work on bringing the Salk vaccine to Canadians and the world.

While Salk could not attend, Connaught sent John Sparkes, co-chair of Connaught's Heritage Committee, to receive the laboratory's award. Paul Martin, Jr., the Minister of Finance, accepted his father's award. As Martin later recalled,

“This was the first time I had heard of the possible late-effects of polio.” It was also at this event that Martin “recalled my memories of the disease for the first time in decades and saw personally by looking around the room that polio was still a challenge for many of the survivors, some of whom were affected by post-polio syndrome.”

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The official 40th anniversary of the introduction of the Salk vaccine in Canada began on April 12th with a feature on CBC Radio’s *Morningside*. Host Peter Gzowski interviewed Jeanette Shannon, a polio survivor and Chair of the Ontario March of Dimes Post-Polio Committee, and me. We discussed the history of polio in Canada leading up to the development and introduction of the Salk vaccine, as well as the personal impact of polio and post-polio syndrome.

Shannon, stricken by paralytic polio in Hamilton in 1947 at age 11, told Gzowski that she remembered April 12th, 1955 very well. “I was in high school, and I came home, and my mother told me about it. Everybody talked about it. They were looking for a cure for polio, and we fell in each other’s arms and cried. And I have to admit I was very grateful because my nieces and nephews wouldn’t get polio. They were going to get a needle to stop them from having polio. But, at the same time, I think my mother and I cried for me, because it wasn’t a cure.” “Because you had come along too soon?” Gzowski asked. “Yes,” she concurred.

“So it was a mixed blessing... but I think that’s why, if you talk to anybody who ever had polio, they’re very, very strong on everybody in the world getting this vaccine, because we don’t want to see anybody else go through it.”

Media attention to polio and post-polio continued to grow during the mid-to-late 1990s. Building on the coverage of the polio anniversaries of 1993-95 and reinforced by dissemination of information through the Internet, more attention was given to the subject, both in special articles and, indirectly, through references or extensive discussion about the personal polio and post-polio experiences of celebrities. Indeed, a popular subject of post-polio websites has been compiling information about famous people who had polio, starting with Franklin D. Roosevelt.

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The polio and post-polio stories of celebrities better known in the local Toronto area were also the focus of newspaper features during the mid-to-late 1990s. CITY-TV reporter David Onley, who was paralyzed from the neck down from polio at age 3, was the main subject of a December 1995 *Toronto Star* feature, “Living with polio – again.” Onley, 45, the first disabled TV news reporter in Canada, who often filed reports from his scooter or supported by his crutches, found his fatigue and weakness getting worse until he “really hit the energy wall.” He thought “Okay, that’s it. I just can’t do this anymore.” Unable to work past

noon and considering taking a permanent disability leave from the job he enjoyed at CITY-TV, he discovered that a program of vitamins made him feel less tired and stronger. “My energy levels changed dramatically.” Onley later became Lt. Governor of Ontario.

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In a September 1998 *Toronto Star* feature, “Epidemic Echo,” the focus was less on celebrities with polio than on practical approaches to managing the effects of post-polio syndrome. The article focused on Jeanette Shannon’s original 1947 polio experience, her long recovery and her recent struggles with post-polio syndrome, which had forced her back into a wheelchair. Also featured was Barbara Dowds, who, together with Shannon, had become a celebrity of sorts among fellow polio survivors in Canada and beyond. High-profile status was made easier through Internet mailing lists and websites dedicated to post-polio information and support.

The “Epidemic Echo” article outlined the latest medical understanding of post-polio syndrome and the most effective means to manage its symptoms. Dr. Neil Cashman, formerly of the post-polio clinic at the Montreal Neurological Institute, and now at the University of Toronto and Sunnybrooke Health Sciences Centre, described post-polio syndrome as “a health problem of epic proportions.”

Dr. Richard Bruno, chair of the International Post-Polio Task Force and

director of the Post-Polio Institute based in New Jersey, the international guru of post-polio, commended Dowds' management of her post-polio syndrome. "You budget your energy," is how she summed up her strategy. "It's a matter of listening to your body, figuring out what I can take and back off a little. You can't sit around and veg. You have to do enough to keep your muscles in good shape, but without overusing them." Bruno, like others, had observed that "most polio survivors have Type A personalities and are over-achievers." While children and adolescents, they would often work 8 to 10 hours each day in physiotherapy, exercising their muscles so that they were able to walk again. "As adults they still perform in exactly the same way, working and exercising, always pushing beyond the limits."

In many cases, Bruno suggested, this tenacious attitude was reinforced by the harsh treatment, if not physical and emotional abuse, polio patients experienced from medical staff during their rehabilitation. Others endured taunts from friends and strangers alike. "This also left a mark on them." Thus, many polio survivors simply refused to slow down or use braces, crutches or wheelchairs again in order to help them "stave off the progressive weakness of post-polio syndrome."

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Two prominent Canadian musical celebrities have publicly exemplified this

stubborn attitude to the post-polio syndrome they have experienced since the early 1980s. Their approach to managing their post-polio fatigue has been to reject the energy-budgeting advice of some experts, preferring to exercise intensely to maintain muscle strength, and/or turn to more unorthodox, alternative treatments.

During the Christmas holidays of 1952, Joni Mitchell, then 9, was stricken with paralytic polio in Saskatoon, Saskatchewan, at the end of a major epidemic that hit the province that summer and fall. Looking back on her experience.

Mitchell said polio made her “prematurely adult and stubborn.”

After a widely celebrated musical career from the 1960s through the 1970s, Joni Mitchell found “the ’80s were ... hard on me.” In a September 1998 American radio interview, she recounted the various personal, professional and health challenges she faced. “And ..., I was diagnosed as having post-polio syndrome, which they said was inevitable.” While she seemed to understand what was happening to cause her weakness – she had trouble holding her guitar and had a special model built that contoured to her body – she gave up on regular western medicine and pursued alternative treatments, which she found “did some mysterious good [for my] problem, and I feel fine.”

In another newspaper interview in September 1998, Mitchell said “I’m opposed to the AMA’s [American Medical Association] diagnosis for post-polio syndrome, which says don’t exercise, lie down and die, basically. Now I’m proceeding through polio as I did in childhood, with the attitude that I’m not a

cripple.”

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It was unclear how long Joni Mitchell could maintain this defiant attitude towards her post-polio condition, an attitude she shared with her friend, fellow Canadian music legend and polio survivor, Neil Young.

After being asked about Mitchell’s post-polio condition in a 1995 British interview, Young explained, “I’ve had that too. It affected me particularly in the mid-80s, when I couldn’t even pick up my guitar. My body was starting to fall apart on me. That’s when I started ‘working out.’ It’s proven to be my salvation too. Lifting weights and exercising have completely changed everything for me, with regard to my health.”

“Scary,” was how Young remembered his polio experience during the extensive interviews he did for Jimmy McDonough’s comprehensive, *Shakey: Neil Young’s Biography*, published in 2002. The book’s title captured the alias names he sometimes used, “Shakey Neil,” or “Bernard Shakey,” which reflected the shaky after-effects of polio. Young noted, “[my] left-hand side got a little screwed. Feels different from the right. If I close my eyes, my left side, I really don’t know where it is – but over the years I’ve discovered that almost one hundred percent for sure it’s gonna be very close to my right side... probably to the left.”

By the mid-1980s, Young struggled to resume his recording and concert work while also managing the care of his quadriplegic son, Ben. But he found himself becoming weaker. Young was having troubles with his record company, which, coupled with the emerging post-polio syndrome, resulted in what many fans and critics described as a series of erratic, uncharacteristic albums.

Recalling the period around the recording of his *Landing on Water* album in 1985-86, Young told McDonough, “I kind of lost it awhile there. *Landing on Water* was the beginning – or the end, depending on how you look at it. I just wanted to try somethin’ else, break out... I felt like I was dying. ...I didn’t have enough strength to lift my guitar up over my shoulder ...pain up and down my arm, pain in my back, pain in my leg.” Young did not know very much about post-polio syndrome at the time, but as he told McDonough, “I’ve been able to beat it by weight-lifting. That was the beginning of my physical reconstruction. It made my music more aggressive.” Like Mitchell, Young’s personal strategy for managing post-polio syndrome seemed to work. However, the specific pattern of both the poliovirus’ original anterior horn damage and the resulting nerve compensation is unique case by case and precludes a single strategy for dealing with post-polio syndrome.

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As the 50th anniversary of Canada’s worst polio epidemic approached, the Ontario

March of Dimes stepped up its 20-year involvement in the effort against post-polio syndrome, officially launching Polio Canada on March 20, 2003. As outlined in a press release in late February, the new organization, funded by Health Canada through its Population Health Fund, would be operated by the Ontario March of Dimes. Polio Canada's National Polio Survivors Network was well in place, with provincial and local post-polio support groups and associations across the country, including in British Columbia, which had long resisted involvement in national polio organizations.

The official launch of Polio Canada was held in Toronto with the sponsorship of Aventis Pasteur Limited (formerly Connaught Laboratories Limited). The event was designed to dramatically link the challenges of post-polio syndrome in the developed, essentially polio-free world, with the realities of new polio cases in the developing world and the ongoing challenges to eradicating the disease from the globe.

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"Cruel ironies are never hard to find these days," *Toronto Star* columnist, Helen Henderson, wrote to start her March 8, 2003 column, "Polio survivors losing important services. So perhaps it's not surprising that this month, which happens to be polio awareness month, Ontario polio survivors are losing critical services in a clinic that has played a key role in their battle to overcome the devastating after-

effects of the disease.” She was referring to the decision by the West Park Healthcare Centre to reduce the services offered at its Post-Polio Clinic at the end of March 2003.

The West Park Post-Polio Clinic had been regarded internationally as “having the ideal team approach to helping minimize polio’s cruel after-effects.” After March 31st, however, due to the hospital’s efforts to manage rising costs within the strict “formula-based funding constraints” imposed by the provincial ministry, the Post-Polio Clinic would consist of one doctor and a receptionist. Post-polio patients requiring physiotherapy, occupational therapy and specialized foot care would “simply be referred to standard community resources.”

Despite a determined letter-writing and lobbying campaign to the Ministers of Health at Queen’s Park and on Parliament Hill, lead by Andria Spindel, Executive Director of the Ontario March of Dimes and Jane Atkey of the Toronto Peel York Post-Polio Committee, the decision did not change.

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It was unclear whether or not the lobbying effort to save the West Park Post-Polio Clinic during March 2003 had a realistic chance of success in the fiscally and politically conservative context of Ontario at that time. It is likely that the issue was overlooked because of a new public health crisis then unfolding in Toronto. The first death from severe acute respiratory syndrome, or SARS, occurred in

Toronto on March 5, 2003. The second, the son of the first victim, followed on March 13, a day after the WHO issued a global SARS alert. By March 17, 11 suspected cases of this new mysterious disease had occurred in Canada, nine of which were in the Toronto area.

Through the spring of 2003, the global SARS outbreak dominated the media, especially in Toronto, one of the major global hotspots of the disease. SARS was a public health crisis unlike anything Canadians had seen for many years; indeed, not since the major polio epidemics of the 1950s. While the SARS crisis may have distracted Ministry of Health and West Park Healthcare Centre decision makers from rethinking the Post-Polio Clinic issue, it certainly focused media attention on the polio epidemic era.

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The SARS outbreak coincided with the 50th anniversary of the great 1953 Canadian polio epidemic, and had the media making links between the new threat and Canada's polio era. For example, the headline of the April 25, 2003 edition of the *National Post* read ““We were treated like the plague’ survivors recall. SARS emergency reminiscent of polio outbreaks decades ago.”

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I was often asked by journalists to provide historical context and draw

comparisons to polio and other infectious diseases during the SARS crisis.

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As bad as SARS was in Toronto during the spring of 2003, it was not nearly as critical a public health crisis as the 1953 polio epidemic had been in cities such as Winnipeg or Edmonton. The headline of the *Edmonton Journal* of April 13, 2003, read “Even 50 years later, polio’s effects still felt.” As author Susan Rattan noted, “While new and disturbing illnesses circle the globe,” such as SARS and West Nile Virus, “at least 700 Albertans are still dealing with the last great plague.” Her article focused on several polio survivors and how their personal post-polio syndrome challenges were being managed in the province. Not unlike Toronto’s West Park Post-Polio Clinic, in Edmonton one of the first such clinics in Canada faced uncertainties about its future.

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Another *Edmonton Journal* article published in mid June 2003, began with the dramatic headline, “In 1953, long before SARS and West Nile, thousands fell victim to polio in what still stands as Edmonton’s worst medical crisis.” This feature article, also by Susan Rattan, did not mention post-polio syndrome, but focused more closely on the 1953 Alberta polio epidemic, especially the situation in Edmonton, highlighting the dramatic experiences of several polio survivors

who needed iron lungs. As Rattan underscored, the Edmonton polio crisis “eclipses the infectious disease outbreaks we’ve seen in Canada in the last year.” The article noted the 8,878 reported polio cases in Canada in 1953, compared to the 409 probable West Nile cases in 2002 and 400 suspected or probable SARS cases so far in 2003.

Rattan interviewed me for her article, focusing on the importance of the role provincial governments played in managing polio epidemics and their aftermath. The ironic part of the 1953 polio story, however, when compared to the 2003 SARS and post-polio stories, is that provincial governments in Canada took a proactive position against polio long before Canada had public hospital or medical insurance programs in place. This was particularly true in Alberta during and after the 1927 epidemic and, on a larger scale, in Ontario during the 1937 epidemic.

However, as was apparent in the spring of 2003, in an age of well-developed public health insurance across Canada, the governments of Ontario and Alberta had a difficult time finding the relatively modest funding needed to support specialized post-polio clinics in Toronto and Edmonton.

The SARS crisis forced significant changes in Canada’s provincial and federal public health and infectious disease control systems and infrastructures, much as polio had during the epidemic era. However, it must be noted that during the 1920s through 1950s, Canadian public health leaders and politicians were well

experienced with a variety of public health threats and their control. Since polio was brought under control with the Salk and Sabin vaccines, a generation of doctors, public health officials and politicians, has grown up and assumed leadership roles with limited professional, political or personal experience of epidemic-proportion infectious disease, especially wide-spread, middle-class public health threats like polio or SARS.

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A key factor shaping the Canadian provincial and federal response to polio during the epidemic era through to the introduction of both vaccines, was the personal interest in, if not direct experience with, polio among politicians. As we have seen, the most prominent of those affected was Paul Martin, Sr. On December 12, 2003, Paul Martin, Jr. became Prime Minister of Canada, fulfilling a professional ambition first demonstrated by his father. Paul Martin, Jr. had rarely spoken publicly about his personal polio experience, thinking little about it until he attended an April 1995 event in Ottawa jointly honouring his father, Jonas Salk and Connaught Laboratories.

Martin said little more about his experience until a May 2002 Rotary International corporate fundraising event in Toronto, supporting the polio eradication effort. As the *Globe and Mail's* public health reporter, André Picard, described it, "The name Paul Martin symbolizes many things in Canada: the

powerful politician, the corporate titan, the prime minister in waiting. But today, the Finance Minister will stand before a hand-picked group of the country's leading chief executives and present himself as something else entirely – a polio survivor; a man whose personal and professional life was markedly influenced by the devastating childhood illness.”

Martin, in the interview with Picard, said, “I could have been one of those kids in an iron lung, or worse.” But Martin made a full recovery, earning “himself a place among a group they call the ‘lucky polios.’” As Picard stressed, the \$5 million raised at the Rotary event was “proof of Mr. Martin’s clout, but his call to alms is also rich with historical meaning because it was Mr. Martin’s father who paved the way for a global vaccination campaign.” Martin, Jr. underscored how “Polio is a part of our family fabric. The experience of talking all this through with my father had a tremendous influence on me – much more than my own case of polio. It made me realize the absolute necessity of our medicare system... And the absolute necessity of eradicating polio.”

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In early November 2003, a week before Martin was officially elected leader of the Liberal Party of Canada, the *Ottawa Citizen* published a series of articles by Mark Kennedy entitled “The Private Paul Martin.” The first part began, “The summer of 1946 was nearing an end. It should have been another joyous day for eight-

year-old Paul Martin and his chum, Mike Maloney, a first cousin who spent summers with him at the family cottage in Colchester, Ont... But on this late-August morning, when the two boys awoke, something was dreadfully wrong... 'I don't feel like getting up,' Paul told his cousin. 'My neck is really stiff.' At first, it seemed he had come down with an illness Mike had suffered about 10 days earlier... It was a mysterious ailment, but whatever it was, Mike had thrown it off. But now 'Little Paul' was becoming increasingly sick." Paul's mother, Nell, who had also taken care of Mike, "was alert to this danger and called a sharp young doctor who immediately suspected polio and told her to get Paul to an isolation hospital in nearby Windsor." Paul was rushed to hospital, Mike later recalling, "We were terribly upset about it. In those days, it was like a kiss of death if somebody got polio."

When Martin, Sr. received word of his son's illness, he rushed home from Ottawa on a government plane and "arrived at the hospital to find his son clinging to life." As Kennedy continued, "The polio had settled in the little boy's throat and he was unable to speak... For eight days, the family prayed and waited, and their prayers were answered." Paul survived the disease, although it was thought it would take a year or so for him to fully recover.

Moloney told Kennedy that "As a kid, Paul was always very energetic, almost hyperkinetic, by modern standards. We used to say he was just restless. And the doctors said this restlessness will be increased probably, but don't be

alarmed because he'll get over it in a couple of years." This restlessness did not go away for Paul Martin, Jr., as it did not for Neil Young or Joni Mitchell, or many other less famous polio survivors. The *Ottawa Citizen* article did not mention post-polio syndrome and whether or not Martin has experienced any suggestive symptoms. Paul Martin Jr. considered himself 'a lucky polio,' and one hopes that his luck will last.

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Fast Forward 17 Years to December 2020...