



Survivors Speak:

Audrey King

Few people demonstrate the strength of will and spirit necessary to make a difference more than Audrey King. A lifelong and tireless advocate, Audrey, a polio survivor, knows from personal experience the challenges faced by people with disabilities, and has committed her life to making things better.

Audrey was nine years old, and living near Oxford, England when her father, a member of the Canadian Armed Forces was posted there. She was out biking with friends when she began to feel unwell. The next day an ambulance took her to the first of four hospitals, where she would stay for the next two years.

Initially completely paralyzed, Audrey became intimately familiar with the dreaded iron lung. Eventually she regained some movement in her hands, but has used a



Audrey being picked up for school in London, England.

wheelchair since as well as a ventilator at night.

What Audrey remembers most from her time in hospital was missing her family and friends.

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Sexuality and Post-Polio Syndrome

Dealing with the symptoms of post-polio syndrome (PPS) can seem overwhelming. With the many different issues that polio survivors face, sexuality and intimacy with your partner may not seem like the first item to tackle. However, polio survivors and their partners have sexual needs and they are important to address.

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Note from the Chair, Elizabeth Lounsbury



So much has happened over the past 60 years. I have no idea where the time goes. It was ten years ago that March of Dimes celebrated its 50th

- and if I were asked now, I would say that could have only been 5 years ago!

Just 60 years ago parents were terrified that their children would contract polio. There was no vaccine only deep real fear. It was this constant petrifying terror that found Mothers going door- to-door in the deep freezing cold in January to ask their neighbors to donate dimes to help find a cure. Parents didn't know where to turn for financial help when their child was suddenly paralyzed from polio. This was the birth of March of Dimes.

Over the past twenty five years I have joined many wonderful people all fighting to find help for

their mysterious, newly emerging symptoms. Finally, thanks to March of Dimes we found we were fighting a new polio battle. Together we learned to live with this beast. Ontario's only Post-Polio Clinic was opened as a pilot project sponsored by March of Dimes. Support chapters grew around the province and now with the national growth of March of Dimes Canada, Polio Canada touches both shores, east and west.

In our quest to raise awareness of post-polio syndrome, I have made many friends around the world - Joan Headley from Post Polio Health International and Jeannette Shannon, known to us as Mrs. March of Dimes, to mention just two. Sadly to say we have also lost some of these friends, Jeannette being one. No anniversary celebration would be complete without mentioning Jeanette.

In the future I can foresee that our support groups will grow. The new people dealing with PPS within our

borders will be younger than we were when our symptoms first emerged.

I had hoped by March of Dimes' 60th anniversary to see the eradication of polio, but in 2010, 865 people contracted polio worldwide, many in countries where it had previously been eradicated, with 458 in Tajikistan alone*. Many of those people will immigrate to Canada and we need to be ready for them. If we don't prepare a plan to find them as they come into this country and educate them on how to manage PPS, their future looks pretty bleak.

I feel confident that March of Dimes will once again step up to plate and be there when needed.

March of Dimes, are we ready for the next sixty years?

Elizabeth Lounsbury,

Elizabeth Lounsbury

Chair, Polio Canada

* source, Global Polio Eradication Initiative,
www.polioeradication.org

Polio Canada hosts Polio World Photo Contest

In 2010, the Polio World Committee held a photo contest to celebrate Polio Awareness Month in October. The theme was "We're Still Here" and people from over 15 countries sent in photos of themselves spanning different times in their lives, living with the effects of polio.

The winner was chosen with the help of Elaine Darling, Coordinator of March of Dimes Canada's Designability® program. Elaine helped put together a display at March of Dimes Canada's Annual General Meeting where members were asked to vote on their favourite photo submission.

The winner was Ferdinand Schiessl from Germany, who contracted polio at two years old. He used an iron lung at night for 45 years, using 'Frog breathing' during the day. Ferdinand's photo-collage entry shows him at several stages of his life, with the quote 'My positive attitude to life: Living is beautiful'. Read more about Ferdinand's polio story on his website www.ferdinand-schiessl.com

Polio Canada® would like to thank everybody from around the world that took the time to share their photographs and memories with us.



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“Visiting hours were Saturday and Sunday for 1 ½ hours only, and children under twelve weren’t allowed at all,” says Audrey. “I remember looking out the window at my brother and sisters and just feeling very lonely,” she says.

After discharge, Audrey went to a school for disabled children in London, England. The school was segregated, with the lower floor used exclusively for children with disabilities and the top floor for the rest of the student population. The kids with disabilities had to enter via a back entrance and all their activities were kept separate.

“You could always hear the other kids’ footsteps up above us, and you’d wonder what they were doing,” says Audrey.

Frequent illnesses caused her to miss a lot of school and eventually resort to home schooling, with the help of a retired teacher who lived next door. When the family returned to Canada two years later the Ottawa school for disabled children wouldn’t accept her – “too disabled” they said. Finally, when Audrey was 15 her mother convinced the local high school to accept Audrey. The school secretaries helped her with toileting and other students helped her with books, coats and pushed her to and from school. Even with her patchwork education up to that point, Audrey excelled and was the top Grade 12 student in her school of 2500 students.

It was also after her move back to Canada that Audrey first became involved with March of Dimes. Reverend Roy Essex, a March of Dimes volunteer used to travel Ontario servicing the respirators (ventilators) of polio survivors. Audrey was one of the many people who benefited from his efforts.

Audrey went on to Carleton University where she trained as a psychologist. She moved to Toronto and worked for thirty years at what is now Holland Bloorview Children’s Hospital, becoming a significant voice for people with disabilities. She has published two books, *Count Me In*, and a book of cartoons called *There’s Lint in Your Bellybutton – A Disabled Fable* which portrays living with a disability with touching humour.

Throughout her working life, Audrey counseled countless families and children living with disabilities, helping them to learn independence and build self-esteem. She has been told repeatedly by the children she saw in her practice, now adults, that nothing was as motivating as seeing another person with a disability with a job, thriving and living life to the fullest. It gave them the confidence and belief that that they could do the same.

Audrey became re-involved with March of Dimes in the late 1970s and became a Board Member in 1982, at which time she helped inaugurate the first Post-Polio

program in Canada. She founded the Toronto-Peel Post-Polio Group, which recently celebrated its 25th anniversary. Audrey also founded a consumer organization for people using ventilators, Citizens for Independence in Living & Breathing (CILB). She has helped influence government policy on funding for people who are ventilator users.

For her dedication and long-term commitment as a March of Dimes ambassador, Audrey King was given the 2010 March of Dimes Jeannette Shannon Leadership Award. Established in 2003 to honour the memory of Jeannette Shannon, the award recognizes outstanding/exemplary contributions to March of Dimes by a past or present member of the Board of Directors.

“I think we polio survivors were raised without being coddled, we were raised to be self reliant and independent – and so I always believed I could do anything I wanted, I just might have to do it a little differently,” says Audrey.

“I’ve accomplished a lot, traveled to the most marvelous places and even though my body now refuses to be bullied by my head as I’m getting older... it’s pretty amazing what I’ve been able to do with my life - I’ve really had a full, fruitful life.”

2011 marks the 60th anniversary of March of Dimes in Canada.

The charity was established in 1951 to help eradicate the threat of polio, an often disabling and sometimes fatal virus. Mothers, determined to find a vaccine that would protect their children began a campaign, going door-to-door to collect money for research, one dime at a time. These women were known as the Marching Mothers. Leading the way, with the title of “Chief Marching Mother” was the Right Honourable Ellen Louks Fairclough, PC, CC, OOnt. Ms. Fairclough passed away in 2004 at 99 years old. In tribute to her enormous contributions to the organization, a March of Dimes giving society is named in her honour.

The Right Honourable Ellen Fairclough is a Canadian legend, a champion of women’s rights and was, among her many ‘firsts’, the first female member of Cabinet and the first female Acting Prime Minister. But in 1947, her most important role was mother, when her 15 year old son Howard contracted polio in the family’s hometown of Hamilton, Ontario.

Joan Heels - Ms. Fairclough’s niece and a monthly donor to March of Dimes, remembers the summer her cousin Howard took ill.

“I had been keeping Howard company, because he hadn’t been feeling well, and when he went into the hospital the next day with polio – I had to go into quarantine for two weeks,” she says.

“Howard had been told he would likely never walk again, but he surprised his doctors by walking out of the hospital on two canes. Only my aunt Ellen wasn’t surprised. She told Howard (a wonderful musician) that she knew he’d find the strength, so he could keep playing the organ,” she continues.

After Howard contracted polio, Ms. Fairclough became an immediate activist, advocating for better conditions for all of Hamilton’s polio patients. Up to that point, those with

polio were kept separated from other patients in small, hot, cramped rooms. Ms. Fairclough campaigned to have them moved into a nearby military hospital that wasn’t being used. She was successful, improving the condition of polio patients dramatically.

Ms. Fairclough also became involved with March of Dimes, first joining the Provincial Board in 1956 and then becoming Chief Marching Mother in 1957. She can be seen below in an iconic photo, leading a group of women as they go door-to-door.

Howard was eventually discharged from the hospital, and his father Gordon, along with Ms. Fairclough, worked diligently to help him strengthen his muscles, allowing him to continue playing the music he loved. Howard suffered from fatigue for most of his life, and began experiencing the symptoms of post-polio syndrome in the 1980s. He passed away in 1986, in part due to polio.

Howard and his mother’s legacy had a huge impact. The support of March of Dimes’ funding – raised by the Marching Mothers, had resulted in the needed vaccine’s discovery in 1955. It is because of the Right Honourable Fairclough, and women like her, that millions of children were spared the devastating effects of polio.

With the discovery of the vaccine, March of Dimes then turned its mission from “cure” to “care” by providing support, first to polio survivors, then expanding its mandate to provide a wide range of much-needed services to children and adults with any type of disability.

March of Dimes now serves over 50,000 Canadians annually, but hasn’t forgotten its roots. Services continue for polio survivors, who are now living with the effects of post-polio syndrome.



Chief Marching Mother Ellen Fairclough leads women in Hamilton, Ontario.

Sexuality and Post-Polio Syndrome

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Sexual intimacy can strengthen self-esteem; create intimacy with your partner, and act as an important source of pleasure, and relaxation. Sexual activity has been shown to boost the immune system, relieve stress, burn calories and even reduce pain in some circumstances.

Straight Talk

Symptoms of PPS do not directly cause impotency or sexual dysfunction. However, PPS does affect energy levels – and energy plays an important role in sexual activity and libido.

As with any other physical activity, polio survivors must approach sexual activity with a sense of balancing energy expenditure and pacing their lifestyle to match their sexual priorities. To put this idea into context, the amount of physical effort required for a person to achieve an orgasm is equivalent to climbing a set of stairs. Just as balancing how often a polio survivor decides to walk up stairs, so too must they create a sense of equilibrium with acts of intimacy throughout daily life.

Readjustment and Planning for Success

Couples can benefit from having open discussions about their desires and how to achieve them. Along with open communication with your partner, here are some guidelines to consider:

- Remember that it takes time to rediscover what works best for you as a couple.
- Expect a certain amount of frustration. As much as possible,

maintain good humor and don't take setbacks too seriously.

- Break away from typical stereotypes – just because someone is aging, doesn't mean that they don't enjoy sex.
- Take care with personal hygiene and appearance.
- Different degrees of muscle weakness may require adjustments in seeking a comfortable position for sex. It may be further complicated by muscle stiffness, bowel or bladder incontinence, fatigue, vision problems, and lack of balance.
- Keep an open mind - there are many ways to enjoy sex besides intercourse! The tenderness and warmth conveyed in cuddling and touching can be a continuing source of physical satisfaction and fulfillment.
- Your doctor can help by providing information, clearly discussing sexual function, arranging for sexual counseling if necessary, or by prescribing medications.

To learn more about this topic, check out these great resources:

The Ultimate Guide to Sex and Disability: for All of Us Who Live with Disabilities, Chronic Pain and Illness. Miriam Kaufman, Cory Silverberg and Fran Odette.

Enabling Romance: a Guide to Love, Sex and Relationships for the Disabled. Ken Kroll & Erica Levy Klein

Post Polio: A Guide for polio survivors and their families. Ch.25, Dr. Julie Silver, M.D. ■

Taking the Confusion out of Estate Planning

Leaving a legacy and estate planning can involve complex issues. It's a sensitive subject most people don't like to address, but not having a proper estate plan in place can result in major ramifications for your loved ones. March of Dimes Canada, through a partnership with Teresa Chong and Investors Group, has been holding a series of educational financial planning seminars for March of Dimes consumers and donors.

At these seminars, Teresa provides a comprehensive view on estate planning that balances current needs, ensures a comfortable lifestyle, while at the same time structuring assets to reduce tax liabilities (including probate fees) and maximizing the benefits to loved ones and/or favourite charities.

In her educational workshops, Teresa has provided insight on different strategies that suit different family dynamics. With Teresa's guidance, some March of Dimes consumers have been able to create and implement estate plans with significant tax/probate fee savings and enhanced estate assets.

If you are interested in holding an estate planning session for your peer support group, or for a complementary consultation, please contact Theresa by calling **416-491-7400 ext 641** or by e-mailing **Teresa.chong@investorsgroup.com**. You can also contact Margaret Purcell at March of Dimes by calling at 1-800-263-3463 ext. 7342.

Teresa Chong is a Certified Financial Planner at Investors Group with over 20 years of experience in the financial services industry. ■

When you are coming to terms with new symptoms, it is important to know that you are not alone. The most important aspect of Polio Canada® are our member groups, which organize local meetings and seminars, in addition to providing information, support and encouragement. Please contact the local support group leader nearest you.

POLIO CANADA® SUPPORT GROUPS IN CANADA

Southern Alberta Post Polio Support Society

7 – 11 St. NE Calgary AB T2E 4Z2
 Contact: Reny de Jong
 Tel: 403-813-9583
 Fax: 403-281-1939
 calgary@sappss.com
 www.sappss.com

Wildrose Polio Support Society

132 Warwick Road NW
 Edmonton, AB T5X 4P8
 Contact: Glyn Smith
 Tel: 780-428-8842
 Fax: 780-475-7968
 wpss@polioalberta.ca
 www.polioalberta.ca

Lethbridge & Area

2722 – 7 A Ave. North
 Lethbridge AB T1H 1A4
 Contact: Juanita Takahashi
 Tel: 403-329-9453
 lethbridge@sappss.com

Saskatchewan Awareness of Post-Polio

2310 Louise Avenue
 Saskatoon, SK S7J 2C7

Contact: Ron Johnson
 Tel: 306 - 477 - 7002
 Fax: 306-373-2665
 sapp1@sk.sympatico.ca
 www.geocities.com/sapponline

Polio Regina

825 McDonald St
 Regina, SK S4N 2X5
 Contact: Carole Tiefenbach
 Tel: 306-761-1020
 twilf_ecarole@hotmail.com
 nonprofits.accesscomm.ca/polio

Post Polio Network (Manitoba) Inc.

c/o SMD Self-Help Clearing House
 Suite 204, 825 Sherbrook Street
 Winnipeg, MB R3A 1M5
 Contact: Charlene Craig
 Tel: 204-975-3037
 postpolionetwork@shaw.ca
 www.postpolionetwork.ca

Polio Ontario

Over 15 groups throughout Ontario
 Tel: 1-800-480-5903
 or 416-425-3463 ext. 7207
 polio@marchofdimes.ca

Association Polio Quebec

3500 Boulevard Decarie, Suite 263.
 Montreal, QC H4A 3J5
 Contact: Mado Shrivell
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 Fax: 514-489-7678
 associationpolioquebec@bellnet.ca
 www.polioquebec.org

Polio New Brunswick

268 Montreal Ave.
 St. John, NB E2M 3K6
 Contact: Peter Heffernan
 Tel: 506-635-8932
 peterhef@nbnet.nb.ca

Polio Northern New Brunswick

Contact: Claudia LeBlanc
 Tel: 506-548-1919
 sunrayfifty@yahoo.com

Polio PEI

47 Westwood Crescent
 Charlottetown, PE C1A 8X4
 Contact: Stephen Pate
 Tel: 902-566-4518
 stephen_pate@hotmail.com

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