

Tireless HIV crusader inspires awe; Dr. Susan King fights the disease nobody wants to talk about Modest care advocate proves true champion protecting children:[ONT Edition]

[Jerry Langton](#). [Toronto Star](#). Toronto, Ont.: [Jun 3, 2004](#). pg. G.21

Full Text (1013 words)

Copyright (c) 2004 Toronto Star, All Rights Reserved.)Dr. Susan King is an incredibly imposing person. She's witty and easy to get along with. She's not a big person and she uses a wheelchair since developing Amyotrophic Lateral Sclerosis (ALS, also known as Lou Gehrig's disease).

But there is something about her focus, her drive, her intensity, her simple ability through force of will to get things done that inspires awe. Sitting with Dr. King makes you wonder what you've done with your own life.

Such respect doesn't come without accomplishment. "Nobody has done more for women and children with HIV than Susan King," said Dr. Lindy Samson, program director of infectious diseases at the Children's Hospital of Eastern Ontario in Ottawa. Dr. Samson should know. She was trained by King at The Hospital for Sick Children when pediatric HIV was just beginning to appear in Canada.

"Pediatric HIV infection was a neglected part of the whole HIV/ AIDS spectrum," King said. "People didn't want to talk about it, there was just such a huge stigma attached to it that I felt like I had to become an advocate for those who couldn't or wouldn't speak for themselves - somebody had to."

King never wanted to speak for anyone; she wanted to be a doctor. "I chose to study infectious diseases because I liked the idea of curing someone," King said. "And I chose pediatrics because I liked the idea that if you help a child, you're giving them many more years of life."

She was, by her own recollection, ill-suited to take up the banner for any cause. "I was very quiet and introspective," she said. "In 1988, they gave all of us on the HIV team media training and I thought, 'I'll never need that, I'll never be on TV.'"

Less than two years later, King was appearing on live TV answering heated questions on controversial topics at what she calls "huge press conferences." Despite it all, the introvert has not completely gone away. "Being in the public eye has never been my idea of fun," she admitted.

She handled it well. Under King's guidance, huge strides were made in Canada for the treatment of children and pregnant women with HIV. Levels of testing skyrocketed, transmission rates plummeted and people heard about pediatric HIV whether they wanted to or not. "Many people thought it was better to leave the topic alone - politicians were the worst," she said. "But I would want to know if my child was at risk."

She was right. A 1992 CBC story on her findings that HIV infection is possible from blood transfusions prompted strong public reaction. "There were so many calls, they blew the hospital's switchboard," King recalls.

And it wasn't just what she did as an advocate, but what she did as a researcher and doctor. "We never had much money," King said. "What the Center for Disease Control in Atlanta does with \$1 million, we had to do with \$1,000, volunteers and goodwill."

She worked just as hard as a doctor as she did as a researcher and advocate. "If I didn't work as a clinician, being with the people we were trying to help every day, I don't think my research would have been possible," she said.

"Susan King put Canadian pediatric HIV research on the map," said Dr. Ron Gold, retired director of

the infectious diseases department at Sick Kids.

"The way she dealt with so many uptight people in the hospital, all the political and legal issues, and still be an excellent researcher and clinician was just remarkable."

Just how remarkable is hard to describe. One Friday evening in 1987, after a full day as a resident in the infectious diseases department, she handed in her pager. Saturday morning, she had a baby. On Wednesday, with newborn in tow, she presented a research paper at a conference.

"I didn't want to waste any time," she said. "My being a resident and wanting a family was not well received, so I felt I had to work a little harder.

"Once we were able to prevent transmission of HIV from an infected mother to her child, we knew what was necessary was more testing," King said.

"We could bring the transmission rate below 1 per cent if we knew in advance - pediatric HIV is preventable, but only if the mother knows she's infected."

HIV testing in pregnant women soon became a quest for King. "Most mothers want to be tested," she said. "Those who don't say it could jeopardize their immigration or relationship status. But they should get tested; an HIV infection will come out anyway so it's better to know while you're pregnant. That way you have a chance to protect your baby."

Although her battle with ALS has forced her into a form of retirement, King continues her research and activism from home.

"It simply has to be done," she said. "I regret I can no longer work as a clinician, but I have to make sure others carry on."

Her determination in the face of a terminal disease comes as no surprise, considering that, faced with excess free time while on sabbatical, she took up running marathons.

"It was great, but I used to have to change into my running gear while driving up Yonge St.," she said, as though it were what anyone would do after a long day saving lives. "Time was tight," she offered in explanation.

In return for her tireless and effective work, the hospital is holding a tribute dinner "to honour one of Canada's most inspiring medical doctors." Donations will help establish a respite house in Toronto for pediatric HIV patients.

"Many people would raise funds for the disease that is affecting themselves," King said. "I'd rather be remembered for the contributions I've made in an area I've worked for years." "Nobody has done more for women and children with HIV than Susan King"

[Illustration]

Tannis Toohey Toronto Star Dr. Susan King won a major humanitarian award and is a leader in the fight against pediatric HIV AIDS.

Credit: Special to the Star