

# Cochlear implants: the head-on collision between medical technology and the right to be deaf



Lynne Swanson

## In brief

THE DEBATE OVER USING COCHLEAR IMPLANTS to help deaf people communicate with those who can hear continues to rage. Some have welcomed the new technology, but others say the deaf have their own culture and do not need to be “cured.”

## En bref

LE DÉBAT SUR L'UTILISATION D'IMPLANTS cochléaires pour aider les personnes sourdes à communiquer avec les personnes entendantes fait toujours rage. Même si certains ont bien accueilli la nouvelle technologie, d'autres affirment que les personnes sourdes ont leur propre culture et n'ont pas besoin d'être «soignées».

*To write this article, the author, who can hear, used many different interview methods: oral speech, lip reading, sign language with interpreter, fax, teletypewriter for the deaf (TTY) and Bell Relay Services. There was a trilingual aspect to some conversations through francophone Bell Relay operators — yet another sign of this country's unique traditions.*

**T**he parents of deaf children say they often find themselves in the middle of a political melee as they try to determine the best course to follow.

That was the experience of Kelley and Dianne Blair of Woodstock, Ont., as they “agonized and explored all the options” for their son, Lewis. They eventually decided on a cochlear implant for Lewis, who became deaf at 7 months because of meningitis, but at the time they were making the decision many organizations for the deaf were telling governments to stop funding the implants and were demonstrating at provincial legislatures.

They did this because of a conviction that deafness is not a disability requiring medical intervention. Instead, many deaf people believe deafness is a “culture” that comes complete with its own language, traditions, values, schools, theatre, art, writings and social and political structure.

Janice Springford, deaf since age 8, reflects that view when she emphatically declares that “deaf is not bad, deaf is not wrong, deaf does not need to be fixed. What is between the ears is a lot more important than what goes in the ears.”

The possibility of a cochlear implant was presented to Springford by her parents when she was 15. They saved for years so they could send their daughter from British Columbia to the House Institute in Los Angeles, where cochlear implants were being pioneered by Dr. William House. “My parents thought I had lost something and should get it back,” she says. “They thought it should be a priority in my life.”

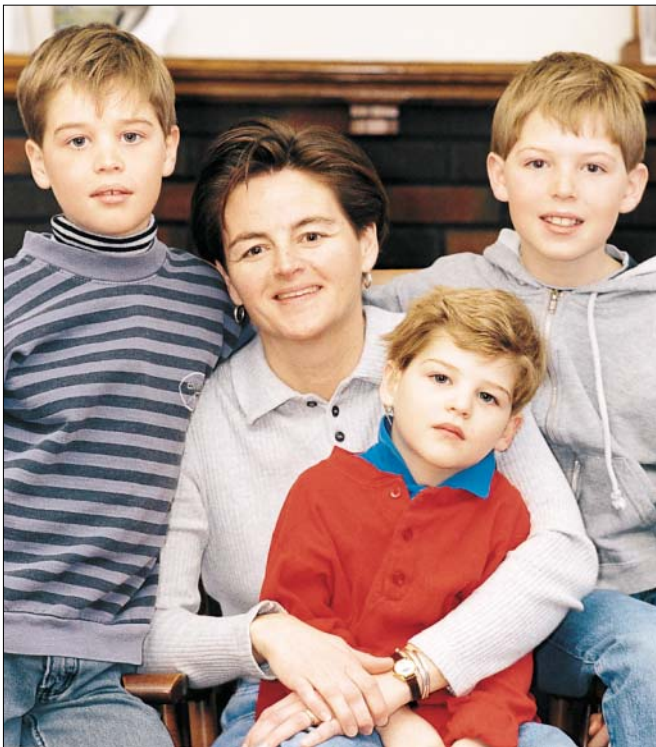
However, after she explored and researched the idea, Springford concluded that “from my perspective, my life was normal. I was normal.” Although deafness had been “traumatic” when it occurred while Springford was in Grade 3, she was “very young, adaptable and open-minded.” By the time she was offered the

## Features

## Chroniques

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*Bill Ironside, London Free Press*

**Dianne Blair holds son Lewis, who has a cochlear implant, as his brothers Liam (left) and Sam look on**

cochlear implant she was an adolescent well adjusted to deafness. She declined.

She went on to obtain a degree in psychology from the University of British Columbia and today teaches at an Ontario school for the deaf. Now 31, Springford has not regretted her decision, “not once, not for a single solitary second. Parents are often so concerned that the child is handicapped that they may not see all the choices and possibilities open to them.”

“Giving Lewis all the opportunity we could” was why the Blairs decided their son would have an implant; 2 attempts to use hearing aids had failed. His parents had considered lip reading and sign language, and they had tried the auditory-verbal approach that employs residual hearing, but results were discouraging.

“We felt if Lewis had some hearing and some language, it would give him more options than if we pursued just sign language,” says his mother.

“This decision was not taken lightly,” adds his father.

At age 2, Lewis received his cochlear implant at University Hospital in London, Ont. Three years after the surgery, his parents are convinced they made the right decision. [In London the procedure costs \$36 748, including the cost of the implant and 2 days in hospital. — Ed.]

Following surgery, he received intensive auditory-verbal training, attended a preschool for hearing-impaired

children and had daily lessons at home. He recently scored well above his age group in a standardized language test.

Kelley Blair says newer, 22-channel implants mean his son “can detect and articulate far more of the frequency range. . . . He speaks in full sentences and his speech is clear and distinctive. He hears the full spectrum of sound . . . and his audiogram [results indicate that] he can hear low, high and middle frequencies all about basically the same as a normal person, except he can’t hear them as well.

“It’s quite amazing what Lewis has done, and there are other kids who have had the same results or better. The implant is a phenomenal device.”

Dr. Lorne Parnes, the otolaryngologist who performed Lewis’ implant — he has completed the procedure about 65 times — says cochlear implants involve a “personal choice.” They are frequently chosen by hearing patients who become deaf as adults and “want to get back into hearing society.” Although they may not restore full hearing, they allow them to do that.

Parnes says 80% to 90% of deaf children live with hearing parents and siblings. “It’s the decision of parents to make whether their children should be part of the hearing or deaf society,” he says. “We as parents are constantly making decisions about our children’s well-being, and this is one them.”

He says parents wanting to make an informed choice will examine all the options open to their child, including deaf culture. Parnes says most deaf parents of a deaf child are unlikely to even consider a cochlear implant, and adults who have been deaf since birth are unlikely to contemplate it for themselves.

Parnes thinks the controversy surrounding cochlear implants may be lessening. “If you look at people who have had the implants, you can’t argue with success.”

## A deaf physician

Dr. Hartley Bressler, a Thornhill, Ont., family physician who has been deaf since birth, sees both hearing and deaf patients in his practice and remains concerned about media reports that tell of “star cochlear implant recipients. The news headlines sensationalize one child’s ‘miracle of hearing,’ but the failures are never portrayed. I understand that most parents want the best for their deaf child, but good intentions do not guarantee success.”

He argues that one-on-one testing by therapists does not simulate “communications most people experience in the hearing world. The research [concerning] cochlear implants is still in its relative infancy [and] there are still too many unknowns and we are on a continual learning curve as to its use, effectiveness and long-term ramifications.”



Although Bressler agrees that many adults are satisfied with their cochlear implants, he asks: "Should we really experiment on deaf children?"

Of particular concern is the inability of a 2-year-old to provide feedback if an implant is causing problems. "All options must be weighed very carefully."

Kristin Snoddon, one of Canada's first cochlear-implant recipients, recalls the period after she received her implant in 1990, at age 15, as "the darkest period of my life. When my parents confronted me about this implant . . . I was shocked, because I did not think there was anything wrong with me physically, emotionally and mentally."

Despite being a popular straight A student in a mainstream classroom, "it was like my parents were telling me there was something horribly wrong with me."

Snoddon, deaf from age 5 because of meningitis, remembered sound and voices. She was disturbed that the implant was "not like hearing at all — it was like vibrating in my skull [and] was very annoying. I have a lot of visual concentration that keeps me very alert to my surroundings and the implant distracted me from what I could see."

Bressler is troubled that other deaf children may eventually share Springford's and Snoddon's reactions to what their parents have done or suggested. "Deafness is not something you should make a child feel defective or in-

complete about," he says. "I wonder about the future self-esteem of a child who is aware that she or he has undergone major surgery for a prosthetic device, not to save life but to please parents."

Bressler knows that health care professionals and the deaf often see these issues much differently. If a group of hearing physicians, psychologists, educators, audiologists and therapists and a similar group of deaf professionals "each write textbooks on the cochlear implant and its surrounding issues, I can assure you they will be diametrically opposed."

Parents in the process of deciding what is in a child's best interest will often be caught in the middle of this "mind-boggling" debate. Bressler, who frequently consults parents of deaf newborns or children, sometimes receives thick files of detailed reports from various specialists and educational experts.

Even when a 3-year-old has not yet spoken, "not one reference is made to the possibility of sign language or any suggestion of meeting someone in the deaf community." In-

stead, there will be a diagnosis of autism, pervasive developmental disorder "or some other esoteric diagnosis.

"Parents then tell me they have never been introduced to the concept of signing and deaf culture," says Bressler. "If they are not interested, that's fine, but at least they should be told to invest a significant amount of time before deciding against it. I will support them if they want a



**Kristin Snoddon: stopped using her implant**

## Cochlear implant, yes or no?

Deaf family physician Hartley Bressler says several questions should be answered before a decision is made to proceed with a cochlear implant. The questions concern the way a successful implant is defined.

Will a successful implant mean I'll be able to hear like hearing people?

Is success the ability to communicate like hearing people, without any obstacles or barriers and without being dependent on assistance?

Is the measure of successful language/communication the ability to learn a word at a time after hours of repetitive rote learning?

Are recipients using the implant as an adjunct for lip reading? (If the answer is yes, this cancels questions 1 and 2.)

Is success measured against the academic and educational achievements of hearing or deaf people?

Finally, is success based on the notion that a cochlear-implant recipient will be able to integrate into the hearing society as one of its better, more successful and productive members?

If an affirmative answer to the final question is used to define success, says Bressler, it means that "all the successful deaf physicians, lawyers, PhDs and other professionals in the world" have been discounted.



cochlear implant, but only if there is true and legitimate informed consent.”

For communication purposes, he advocates signing in addition to speech, not one or the other. “There is no evidence that learning to sign first will get in the way of speech training. In fact, it will enhance it.”

Even if parents decide on a cochlear implant, Bressler suggests that learning American Sign Language (ASL) before verbal-auditory training will provide youngsters with language skills, and this can provide structure and fluidity when they begin developing oral and written language skills.

To promote informed consent, Bressler arranges for parents to meet deaf people. The first meeting will involve someone with oral but not sign-language skills, and the next with a person who has only ASL. “Finally, I introduce them to someone who has both. They may not be sold on one idea over the other, but this gives an idea of how people function as deaf adults. Parents are extremely appreciative of this eye-opening exposure. All options should be placed on the table for all to see. No one side is right and the other wrong.”

Chris Kenopic, president of the Ontario Association of the Deaf (OAD), stresses that his organization agrees “parents have the right to decide what they want for their child, as long as they are provided the full information and understand all the options.”

However, he thinks that because hearing society considers deafness “something that needs to be fixed,” specialists may not suggest all options to parents. Kenopic emphasizes that OAD is not concerned about “losing [the] native language [ASL].” He is concerned that some physicians have used this argument, “mak-

ing [parents] hesitate to meet deaf adults” to explore alternatives.

The OAD recognizes that funding of cochlear implants will continue. Kenopic says efforts are now being made to make resources available to help hearing parents understand the needs of deaf children.

Only now, 16 years after she became deaf, is Kristin Snoddon “breaking into deaf culture.” Ironically, it was the challenges that came with living with her 22-channel implant that led to her “awakening” as a deaf person. She stopped using the implant when she was 19, 4 years after receiving it. The same year she entered the University of Toronto, where she graduated with an honours BA degree this spring.

Although she learned some sign language, Snoddon thought deaf people may have rejected her if they knew about the implant. “It’s very difficult to be rejected by your peer group,” she says.

Meeting other deaf people and discovering deaf culture proved a “totally revolutionary thing” with “a tremendous impact on every single area of [my] life,” she says. “I accept my differences now that I am aware of the deaf culture. My self-esteem has really increased.”

Snoddon required further surgery last year to remove her implant because of a “life-threatening” complication. If her family had been helped to understand her as a deaf person, says Snoddon, many personal, emotional, medical and other problems may have been avoided.

Despite the intensity of the controversy, Bressler thinks “we should have an open mind. I may have deafened ears, but one must have open eyes to look at both the deaf side and the nondeaf side.” He hopes everyone becoming involved in the debate will enter it with eyes open. ?