

# Hearing loss gives NJ native his voice

by Nancy Sokoler Steiner

Michael Chorost climbs the flight of stairs to a room filled with metal file cabinets. He's never been to this place before, but he is greeted like a long-lost relative. A smiling woman hands him what he has come to see: file number 27392.

The 40-year-old science writer opens the file and sees a photograph himself as a young child. He picks up a note, postmarked 1968 in Westfield, NJ, and written in his mother's familiar hand: "I have a three-and-a-half-year-old son who is hard of hearing. I understand you have a correspondence course of materials for such children and would like to enroll. Thank you."

Chorost's mother, Susan, wrote these words to the John Tracy Clinic in Los Angeles soon after her son was diagnosed with severe hearing loss. In return, she received a personal letter and the first in a series of lessons designed to guide parents of young children with hearing impairment.

His mother's letters to the clinic, founded in 1942 by Spencer Tracy and his wife, Louise, were the first steps in a journey through hearing loss that Chorost has described in his book, *Rebuilt: How Becoming Part Computer Made Me More Human* (Houghton Mifflin, 2005).

That journey — from a severely hearing impaired toddler in suburban New Jersey to the successful author holding his file in Los Angeles — transcends mere time or geography. For Chorost, it has been a journey from alienation to acceptance, from bystander to participant, and from deafness to hearing.

Chorost (pronounced Kor-ist) recently traveled to the clinic from his home in San Francisco to speak to an audience of adults and children about his experiences with hearing loss.

In an interview beforehand, he explained how he spent his first three-and-a-half years of life able to hear loud sounds but unable to hear speech. Today, such a condition would be identified by two months of age, notes Barbara Hecht, president of the John Tracy Clinic. Early diagnosis is crucial for speech acquisition since children who haven't acquired fluent and natural diction within the first four years of life are unlikely ever to develop it.

With hearing aids, Chorost could function adequately in a hearing world. The John Tracy correspondence class helped his mother meet her son's special educational, social, and emotional needs, and Chorost went on to attend both the Summit Speech School and public school in Westfield.

A bright and inquisitive child, he soon caught up verbally but never felt as if he fit in. "Social norms are not taught; they are overheard, but the one thing even the most skilled deaf people cannot do is overhear," he writes in *Rebuilt*.

The book combines Chorost's analytical scientific approach with a personal, self-deprecating sensibility. He wryly notes, for example, "It took me longer to go from puberty to my first relationship (1976-89) than it took the entire United States government to design and land a spacecraft on the moon (1961-69)."

After earning a PhD in computer technology, Chorost found work as a science writer and educational computing consultant. He led an uneventful and vaguely unsatisfying life until, in 2001, he abruptly lost his remaining hearing.

With his background in technology, Chorost knew about the success of cochlear implants and that he wanted to get one. The device consists of an external microphone and sound processor that looks like a cell phone headset, a processor usually worn at the waist, and a unit implanted beneath the skull that stimulates the auditory nerve via electrical impulses. As of 2002, more than 23,000 adults and children in the United States with profound hearing loss had received cochlear implants, even children as young as one year old.

A cochlear implant does not restore sound; it replaces it with electrical stimulation. When his implant was first activated, said Chorost, "everything sounded like gibberish." It took him long, frustrating months to interpret the signals and hear again.

He also struggled with the idea of becoming, in his words, "a cyborg." It spooked him to be "physically fused" with a

mechanical device that literally mediated his reality. "I had long lived a life surrounded by computers," he wrote. "Now the computer would go *inside* my body, literally woven into my flesh.... I would hear nothing but what its software allowed...."

In the process of writing *Rebuilt*, Chorost gained some surprising insights. "I felt fairly alienated from Judaism for a very long time," said Chorost, who attended religious school as a child but never observed the religion as an adult. "It was in writing the book that...I found Judaism was more a part of me than I'd realized," he said.

Chorost's religious awakening led him to "dip a toe in the water" by attending services in his San Francisco neighborhood. He said the congregation's rabbi, Michael Lerner (founder and editor of *Tikkun* magazine), "has a way of thinking about spirituality and political action which is very consonant with my outlook."

Back at the John Tracy Clinic, Chorost finds another nugget in his file. In one of her progress reports, his mother wrote, "It is my fond hope that we might introduce you someday to our little Mike."

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Chorost today and as a boy

