

Help When Blindness Falls On Deaf Ears

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Jacksonville, Ill. — Imagine the feeling of a curtain slowly drawing closed on all you know of the world, the last rays of light streaming in through a narrower and narrower opening, until at last all around you is a black, silent, permanent void.

The creeping blindness that so afflicts a small percentage of deaf people is Usher`s Syndrome. When it strikes, it robs the victim of sight unpredictably and by degrees while doctors stand by, virtually helpless. Patients grasp at straws.

Five students at the Illinois School for the Deaf (ISD) in this quiet town 45 minutes west of Springfield have been diagnosed as having Usher`s Syndrome. Two weeks ago they began a drive to raise funds for an

extraordinary, perhaps quixotic attempt to arrest or even reverse the progress of their disease by using non-Western medical techniques.

The contrast between the old, venerated Midwestern institution and Grace Halloran, a bubbly Californian who visited to talk up acupuncture,

acupressure, foot reflexology, biofeedback, massage and visualization therapy as treatments for Usher`s Syndrome, was striking. It made one realize how frustrating it must be for the victims, their parents and their teachers to rage impotently against the dying of light.

“We`ve been told for so long that there isn`t much we can do, and now there`s something we can hang on to,” said Sandy Mayer, of Highland Park, who has watched her deaf,

17-year-old daughter Mindy`s field of vision shrink over the last decade so that now her range of sight is little more than 15 degrees. That`s like looking through a tunnel as narrow as the distance between your hands if you hold your arms straight out, in front of your shoulders.

``We`re going to go for it. As far as improvement is concerned, Dr. Halloran is the only one who has held out hope.``

Going for it, in this instance, means attempting to raise \$50,000 to send the students, their parents and selected staff members from the Illinois School for the Deaf for a three-week visit in June to Halloran`s Center for Eye Health Education in Santa Rosa, Calif., an unorthodox clinic that bills itself as the only program in the country to offer self-help therapies and education for people going blind.

The story of the tiny clinic is the story of Grace Halloran, an infectiously upbeat proselytizer who is her own greatest success story.

In the late 1960s she had all her faculties and was an ace keypunch operator at the Pacific Stock Exchange in San Francisco. Quickly and inexplicably, her on-the-job performance deteriorated. She started seeing flashing lights and having minor automobile accidents. Her bosses fired her from the stock exchange, and she began a series of tests to find what seemed to be a brain tumor.

In February, 1970, at the age of 24, she was diagnosed as having retinitis pigmentosa, a degenerative, hereditary eye ailment caused by an enzyme deficiency that ultimately takes away part to all of the peripheral vision and strikes, among its nearly half million victims, 3 to 5 percent of the congenitally deaf population.

The prognosis for Halloran was bleak: Learn Braille, get on disability and don`t have children because there`s an extremely good chance they`ll go blind, too.

After a year-long bout with depression and self-pity, Halloran fought back. She went through with her plans to become a single mother and began exploring her options and educating herself. She studied nutrition, yoga and acupuncture, apprenticed herself to a vision clinic and ultimately earned a Ph.D. in holistic health care from the North American College of Natural Health Science at Columbia Pacific, an alternative university.

She mixed and matched unconventional therapies, once

overloading herself with vitamin A until her skin turned a disturbing yellow, but ultimately settled on a rounded, balanced approach to eye care that seemed to work. Her 13-year-old son whom she treats has no significant vision problems despite doctors' warnings that genetically he was at high risk to become blind by the time he reached adolescence. Her mother and sisters, both afflicted with retinitis pigmentosa, have improved their sight significantly.

But most dramatically of all, Halloran has gone from being legally blind with a 5-degree field of vision to having functional 20-40 vision with an 80-degree field of vision, a reversal her ophthalmologist calls

``extraordinary.``

Halloran spent six years in private practice administering vision therapy. Last June she formed the eight-member Center for Eye Health Education. Her staff includes experts in biofeedback, massage, acupuncture and acupressure, but no medical doctors. The 21-day client training program, which uses no drugs or surgical techniques, costs \$2,350, a fee that most insurance policies do not cover.

Much of the program deals with stress management, motivation, positive thinking and learning to manage the handicap of limited vision.

She promises no cures but offers that 85 percent of the 14 clients she takes in during each monthly session show significant, documentable improvement in either acuity, color perception or field of vision. Indeed, some of her results, as certified by nonmedical optometrists, suggest what the Western medical establishment believes impossible, that her treatments cause the regeneration and healing of damaged sensory nerve tissue.

“Who knows?” asks Dr. Paul Archanbeau, a Santa Rosa ophthalmologist who has observed Halloran’s work and has examined the data she has gathered.

“In the medical community we approach things like this with caution because we’ve all been burned before, but I can tell you that what Grace Halloran is doing looks bona fide to me, and her results are promising. It looks like she has something.”

A prestigious eye research foundation in San Francisco has taken a keen interest in Halloran’s work and will commence a rigorous clinical evaluation of her work later this year.

Most of those who attend the center are middle-aged adults without significant hearing disorders. If the fundraising efforts at the Illinois School for the Deaf are successful, Halloran will have her first group of patients with Usher’s Syndrome.

Extremely rough guesses put the number of deaf children with Usher’s Syndrome nationwide at 300. Many will end up

like Tanya Turner, 12, of Danville, Ill., the most severely afflicted of the five ISD students. Over the last two years her field of vision has gone from normal to about 3 degrees, which is like the width of your fist held at arm's length. For her, sight is equivalent to looking at a silent world through a small keyhole.

Halloran is working with ISD by chance. She was the subject of a very flattering P.M. Magazine TV profile last winter that a friend of an ISD administrator happened to watch. When the rough details made their way back to the school, officials got on the telephone and tracked down Halloran.

Until that time we were totally stumped, said Tom Butterweck, ISD's director of clinical services. We had no way to work with these children. The Usher's students at ISD range in age from 11 to 18. The school has no supplemental monies for their care and says that state funds are not available to pay for their treatment at the Center for Eye Health Education.

Halloran organized and began to publicize Flight for Sight, Help the Children, including solicitations to charitable foundations and a runathon in California. There has been no push in Illinois to raise money for the children.

At her own expense, Halloran flew here March 21 to meet with media representatives, interested ISD staff members, parents of the affected students and, after the parents made a firm decision to try Halloran's treatment, with the Usher's students themselves.

I'm an alternative person, Halloran said. Mine is a grassroots organization. I've been told that I'm pioneering a field that doesn't really exist, but that's okay with me. Skepticism is okay. I believe that what I do will stand on its own merit.

I'll tell those kids, if I could do it, you can do it. If it works, it works because you do it.

Donations for Flight For Sight may be sent to the Illinois School for the Deaf, Jacksonville, Ill. 62650.